Provincial Renal Advisory Committee Report

Framework for the Development of a Provincial Kidney Program

April 2003

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EXECUTIVE SUMMARY

Mandate

The Provincial Renal Advisory Committee was established in December 2000 with a mandate to advise the Department of Health and Community Services on issues related to the planning, development, implementation and evaluation of renal services for the Province.

Committee members were appointed by the Minister of Health and Community Services and are representative of the following groups and organizations:

- Department of Health & Community Services
- Nephrologist
- Kidney Foundation
- Western Dialysis Services
- Central West Dialysis Services
- Eastern Health & Community Services Satellite Dialysis Service
- Program Manager and Program Director, Health Care Corporation Dialysis Program
- Provincial Organ Procurement Program

A listing of participants is included in Appendix III.

In keeping with the mandate, the Committee has reviewed the current kidney disease services and program components in the Province, and has prepared this document with recommendations for the provision of a comprehensive Provincial Kidney Program focussing on disease prevention, health promotion and treatment options.

Format of Report

This report proposes a Framework for the Development of a Provincial Kidney Program for Newfoundland and Labrador. The incidence of Kidney Disease is growing and this report examines the need for coordinated kidney services throughout the Province. Changes in population are examined in Module A and provides demographic information for each region of the Province. Pages 3 to 6 include a Table of Recommendations which are supported by the Provincial Renal Advisory Committee. These recommendations are extracted from specific components supporting a Provincial Kidney Program including: Prevention and Treatment of Chronic Progressive Kidney Disease (Module B); Peritoneal Dialysis (Module C); Haemodialysis (Module D); Kidney Transplantation (Module E) ; and, *Institution and Community Based Satellite Haemodialysis Units: A Comparison of Models in Stephenville and Clarenville* Report (Module F). Because of the vast volume of information related to this subject area, modules are attached for ease of reference and shall be referred to in the body of this document.

This report also provides the preferred option for a model of Haemodialysis Services including a comparison of five sites in the Province and finally, recommendations for a plan of action to move forward with the development of a Framework for a Provincial Kidney Program for Newfoundland and Labrador.

Summary

The provision of kidney care services to a decreasing population across a vast rural geography, while at the same time maintaining quality, accessible and sustainable services, is a great challenge to the health system. Patients who live in rural areas often have to go further to access their services and individuals in rural areas requiring dialysis services often drive long distances or relocate from their homes. The Advisory Committee has been challenged to develop a plan which takes this access issue into consideration, while balancing the availability of trained human resources to provide direct and supportive services and the need for a quality of life for individuals who require treatment.

There is no provincial mechanism currently available to coordinate the comprehensive planning, development, delivery or evaluation of health services for people with kidney disease. The required skills and resources to provide these services do not exist uniformly throughout the province, although people affected by kidney disease of all levels of severity reside in all regions of the province.

The Provincial Renal Advisory Committee recognizes that a coordinated plan of action which addresses both the prevention and treatment of kidney disease will work to reduce the incidence of the disease and provide services which are reasonably accessible and sustainable. While developing the plan, the Committee has taken all of the challenges into consideration, and has endeavoured to provide a balance which will result in improved access to standardized quality care across the province for individuals and families. Based on these considerations, the Provincial Committee recommends a Provincial Kidney Program be established in keeping with the recommendations outlined on page 3 of this report.

Finally, the recommended model for haemodialysis satellite services would be one that is located in the community but administered by a Regional Institutional Board responsible for hospital services. This is primarily because of access to a larger pool of appropriate human resource personnel and other related supports as evidenced by the evaluations of the pilot satellite units in Clarenville and Stephenville. The Committee recommends proceeding with the development of a satellite unit in the Conception Bay North and the Central East areas based on analysis presented on pages 10 - 14 of this report. This is contingent on the implementation of the coordinated Provincial Kidney Program.

TABLE OF RECOMMENDATIONS

Framework for a Provincial Kidney Program

1. Incorporate a focus on prevention of kidney disease as an explicit objective in relevant health promotion and prevention programs in the Province (e.g. those expected to impact on the incidence of diabetes, high blood pressure and atherosclerosis). This is inherent in the overall strategy for the Provincial Kidney Program

2. Establish a full time Provincial Coordinator to support the Framework for the Development of a Provincial Kidney Program. This position will oversee the coordination of policies and guidelines for management of haemodialysis units and engage Regional Health Board stakeholders and the Department of Health and Community Services.

3. Establish a part time Medical Director who is a certified nephrologist to provide consistent clinical expertise to the Program.

4. The coordinated Provincial Kidney Program shall have a mandate to:

    - coordinate and facilitate interaction between existing agencies in the planning and delivery of kidney disease care ensuring input from policy makers, administrators, health care providers and consumers,
    - develop standards and policies for kidney disease care,
    - plan for modification of existing services,
    - evaluate the need for kidney care services across the Province,
    - plan for the development of new services as determined by need,
    - develop an acceptable mechanism for province wide tenders and purchase of equipment and supplies, and
    - partner with provincial and regional authorities to secure the resources needed to provide kidney disease care.

5. Develop a Provincial Evaluation Implementation Committee which ensures effective and quality services. This includes evaluating compliance with developed standards for all aspects of care. Evidence of quality care will come from compliance with standards reports, patient/service provider satisfaction surveys and key informant interviews. This Committee shall intervene via existing Provincial and Regional authorities in cases where standards are not being met.

Prevention and Treatment of Chronic Progressive Kidney Disease (CKD)

1. Initiate a timely screening program for those at risk for CKD based on established criteria. A screening program for the general population is not recommended

2. Incorporate concepts of the chronic disease care approach when redesigning the primary care system, aimed in part at enhanced management of CKD with the aim of preventing associated cardiovascular events and kidney disease progression

3. Provide resources and support for interdisciplinary care for those with advanced CKD at additional sites within the province. This should be done in conjunction with the nephrology outreach services already in place.

4. Promote the timely involvement of healthcare professionals specializing in kidney disease in the care of those with advanced CKD.

Peritoneal Dialysis

1. Responsibility for placement of peritoneal catheters, education of patients with regard to treatment modality selection, medical and nursing follow up of patients continue to be shared between the Health Care Corporation of St. John's and the Western Health Care Corporation. Staff at the Western Health Care Corporation should be responsible for provision of services to patients residing within their catchment area.

2. Responsibility for peritoneal dialysis services in the remainder of the province should remain vested with the Health Care Corporation of St. John's. Medical outreach from St. John's is currently meeting the needs of patients on dialysis from all other regions. It is not anticipated that Nephrology services will be available in sufficient depth outside of St. John's and Corner Brook to permit outreach services in any other location in the province in the foreseeable future.

3. Interdisciplinary pre-dialysis clinics should be established at some other regional centers in Newfoundland and Labrador. These clinics should co-ordinate with the travelling nephrologists from St. John's. Clinic staff will require specific training in education of patients and families with regard to end-stage kidney disease and its treatment. This education should be coordinated with that currently offered through the Health Care Corporation of St. John's and Western Health Care Corporation. Offering education in regional centers in support of travelling Nephrology clinics is vital to support the uptake, when appropriate, of home-based dialysis modalities by patients and families.

4. Explore cost efficiencies related to home support services for patients on peritoneal dialysis. Patients may choose this modality if services are provided in the absence of family/caregiver supports.

Haemodialysis Units

1. When determining the feasibility of a community or institutional based satellite unit various factors, including thorough research, have to be considered. These include:
    - the number of people requiring service;
    - distance to existing service;
    - the availability of specially trained staff, including medical, nursing and support staff;
    - appropriateness of service delivery model and the availability and capacity of in-centre units for back-up support;
    - availability of appropriate space, equipment and supplies;
    - the Provincial Kidney Plan; and
    - cost implications.

2. Planning for new satellite units would be in the context of the Provincial Kidney Plan and include determining the resources needed centrally by the in-centre institution to effectively manage one or more units.

3. Establish policies and guidelines regarding nephrologist visits to satellite units.

4. Develop a plan inclusive of managerial, nursing, technical and biomedical services including guidelines and policies regarding backup staffing for satellite units. Training is also necessary to ensure staff maintain their skills.

5. Establish a phased-in approach to establishing satellite dialysis units in Conception Bay North and Central East. This requires planning within the context of the Provincial Kidney Program including the assessment of resources needed by the in-centre institution to effectively manage each unit.

Kidney Transplantation

1. Develop and fund the capacity for interdisciplinary care for advanced kidney disease in regions where dialysis services are provided to ensure appropriate education and uptake of all treatment options including transplantation.

2. Ensure the OPEN (organ procurement) program has the necessary resources to maintain the existing excellent rate of organ retrieval for transplantation.

3. Initiate a review of the mechanism by which fee-for-service health care professionals are reimbursed for work done in relation to organ retrieval.

4. Create a clear mechanism with provincial scope for review and funding of new immunosuppressant medications used in transplantation.

5. Provide a contingency fund to the OPEN program for timely assistance of those with limited financial resources required to travel out of province at short notice to receive a transplant.

6. Defer the development of a kidney transplantation program in the Province.

INTRODUCTION

Kidney Disease

New end-stage kidney disease (ESKD) cases are occurring at a compound annual growth rate of 7.3% in Canada. In a five year period this province has seen similar trends as there were 77 patients diagnosed in 1995 with an increase to 97 patients in 2000. The medical, social and financial burden posed by ESKD is considerable and growing rapidly. People generally reach ESKD as a result of chronic progressive kidney disease (CKD). Many of the underlying diseases causing or aggravating kidney failure, such as diabetes and high blood pressure, are amenable to primary prevention by population and individual-based interventions. The progress of CKD can be slowed in many cases by appropriate treatment of associated and treatable complications such as anemia, parathyroid and bone disease. In addition, there are strong links between CKD and cardio-vascular diseases. Many people with less advanced CKD will die or suffer complications of cardiovascular disease before ever reaching ESKD. Targeted interventions, such as lowering blood pressure and cholesterol, can substantially reduce the progression of both kidney and cardiovascular disease. Careful management of these complex inter-related diseases and their risk factors requires detailed longitudinal and focused care which is not currently possible in our traditionally organized health service system. Treatment of advanced CKD, prior to dialysis, requires the timely involvement of, and access to, specialized multi-disciplinary teams. Module B further discusses kidney disease trends in Canada.

Dialysis Therapies

Dialysis is a treatment for kidney failure that removes waste and water from the blood. It cleans the blood either by passing it through an artificial kidney machine or by filtering it inside the abdomen. Dialysis may be used as a temporary or long term measure when kidneys have failed. There are two types of dialysis, i.e. haemodialysis and peritoneal dialysis. For haemodialysis, the patient's circulation must be accessed by a surgeon and they are generally required to attend a dialysis unit four to six hours at a time for three days a week. Haemodialysis in a dialysis unit is carried out by specially trained nurses and each patient is seen in the unit by a nephrologist on a regular basis. At present, dialysis units are located in St. John's, Clarenville, Grand Falls-Windsor, Corner Brook and Stephenville. Haemodialysis can be done at home but is relatively technically complex and demands a degree of skill, ability, and availability of a helper, such as a spouse, parent, or other. This renders home haemodialysis unavailable for many elderly who may not have such a helper available on a regular basis. Currently, there are three patients in the Province on home haemodialysis.

Peritoneal dialysis (PD) is a home based therapy which requires the placement of a catheter through the wall of the abdomen. Two to three litres of fluid are instilled and drained alternately through the catheter on a regular basis, usually four times daily. An alternative is to have a machine (cycler) do most of the fluid exchanges at night while the patient is in bed and asleep. This generally reduces the need to change the fluid during the day to a single exchange. The older cyclers were cumbersome, but innovation has led to the development of a smaller portable cycler dialysis machine. This machine is easier to use and the process is fairly easy to complete. Almost all patients suitable for peritoneal dialysis can be managed at home. Many people can learn to perform their own dialysis, while in other cases a family member, relative or friend can perform the treatment. The training time is about five to seven days and the technique is considered moderately "technical". The patient and caregivers are trained to do fluid exchanges using sterile technique, and to measure and record patient weight, pulse, temperature and blood pressure. In addition, they are trained to adjust the fluid concentration necessary to keep the patient's fluid balance in the desired range, to recognize and report complications or health concerns, and to provide guidance to manage common complications at home. The major problems arising from poor technique are abdominal or exit site infections but these can usually be treated successfully. People on home peritoneal dialysis maintain regular contact with peritoneal dialysis nurses at the St. John's or Corner Brook sites.

Cost Associated With Modalities of Dialysis

Peritoneal dialysis is generally considered to be less costly as compared to haemodialysis. Peritoneal dialysis is a home-based therapy generally provided by the patient themselves or their family. Haemodialysis by contrast is usually delivered in-center by health care professionals. There are some professional costs associated with peritoneal dialysis including the costs of training and ongoing monitoring of patients which generally involves trained nurses at an in-center unit. Costs are also incurred in home peritoneal dialysis cases where trained community support workers, through the Home Support Program, are paid to assist these patients. The medical fees for the two modalities also differ. In many Canadian provinces, including Newfoundland and Labrador the medical fee for care of patients on haemodialysis exceeds that for patients on peritoneal dialysis. The costs of supplies and disposables are not that different between the two techniques. The use of high flux dialyzers and lack of reuse of membranes, as is currently the standard in most Canadian centers, contribute to the cost of haemodialysis.

Capital costs to set up haemodialysis units are high as construction of new or redeveloped space has to meet special design features of a dialysis unit. From an equipment perspective, a dialysis machine cost approximately $26,000, a water filtration system costs approximately $60,000 and dialysis chairs cost $1,500 each. Peritoneal dialysis offers the advantage of not requiring the construction or reconstruction of specific space. The alternative option of using home-based haemodialysis does exist but requires much longer training times for patients. The cost of haemodialysis training and equipment are also higher than those associated with peritoneal dialysis.

Several comparative costing studies have been carried out in Canada. A 1995 study from Hamilton suggested that the annual dialysis associated costs for a patient on peritoneal dialysis were $31,900, those for patients on in-center haemodialysis were $54,900 and those for home haemodialysis were $26,000. These figures include costs such as equipment, space, maintenance, utilities, etc. It is important to note however that the costing of the home haemodialysis option requires more technical and expensive training and may require formal home support services. Individual differences among programs with regard to staffing ratios and utilization of supplies over time make it difficult to generalize these figures to Newfoundland & Labrador. Broad trends persist and Canadian-costing studies would support the general trend of these costs. The evaluation of the Clarenville community-based unit revealed the annual cost per patient is $31,700 while the annual cost per patient in the St. John's institutional-based unit is $20,900. This is primarily due to patient volumes and efficiencies created by a larger centre. The costs in this Province do not include equipment, space, utilities, etc.

In terms of cost savings to patients, however, the evaluations of the pilot dialysis units in Clarenville and Stephenville indicated that patients, former patients and family members felt there have been personal financial savings as a result of receiving dialysis closer to home.

Haemodialysis Service Models

Primarily, there are four service models that can be assessed for implementation in this province:

1) **Hospital-based units** - have a full medical team of nephrologists, interventional radiologists and surgeons who provide the vascular access for patients. These units have specially trained nursing staff and other health professionals (e.g. dieticians, social workers, pharmacists, etc.) to provide services to people whose conditions are at a high level of acuity and complexity. The dialysis units in St. John's and Corner Brook are considered full hospital based units.

2) **Hospital-based satellite units** - are generally operated under the direction of larger hospital units described in (1) above. Medical staff supporting these units would not include a nephrologist, interventional radiologist or surgeon on site and for this reason only medically stable patients can attend these units. Care is provided primarily by specially trained nurses while other professional services such as dietician or social worker are generally not available or are available on a very limited basis. At present, the Grand Falls-Windsor dialysis unit is operating between service models 1) and 2). Support from the nephrologists in St. John's is required and provided. The dialysis unit in Stephenville is considered a hospital-based satellite unit.

3) **Community-based satellite units** - operates in a community setting under the medical direction of a hospital based unit described in 1) above. Nursing staff are the only professional staff on site as the units may be located outside the confines of a hospital. Only medically stable patients can be accommodated in this type of unit. The Clarenville community-based unit is presently administered by the Eastern Health and Community Services Board and is located in one of their leased office and clinic buildings.

4) **Patient's home** - where a family member or friend usually performs the treatment. Patients have to be medically stable to avail of this type of treatment. There are three patients on home haemodialysis; one in the Central Region and two in the Eastern Region.

HAEMODIALYSIS UNITS: AN ANALYSIS OF NEED

Current and Future Dialysis Utilization Rates

Table 1: Haemodialysis services are offered to 270 patients in 7 locations. The following table identifies the specific sites and services provided.

Location	No. of Haemodialysis Stations	No. of Patients	Home Haemodialysis
Waterford Site, St. John's	26	114	
Health Sciences Centre, St. John's	13	48	
Western Memorial, Corner Brook	12	47	
Sir Thomas Roddick, Stephenville	4	9	
Central Newfoundland Regional Health Center, Grand Falls-Windsor	12	43	
Health and Community Services - Eastern, Clarenville	3	6	2
Central East Region	0	0	1
Total	**70**	**267**	**3**

Table 2: Peritoneal dialysis services are offered to 73 patients. The following table identifies the specific regions and number of patients.

Region	No. of Patients
St. John's	10
Avalon	12
Peninsulas	13
Central East	13
Central West	6
Western	8
Grenfell	9
Labrador	2
Total:	**73**

Studies of people on both modes of dialysis therapies have generally indicated no difference in survival. The average age of patients receiving haemodialysis is 60 years with a range of 20 to 80+ years old, while the average age of patients receiving peritoneal dialysis is 59 years ranging from 23 to 86 years old. Medical and particularly social factors influence the choice between methods. Geography has dictated that people who live in remote areas or, at a distance from the existing haemodialysis units, generally rely on peritoneal dialysis. Dependent elderly without family supports and those with medical contradictions to peritoneal dialysis must relocate or travel long distances to access haemodialysis as community health nursing and home support resources are limited. This has led to requests for provision of haemodialysis in areas where this treatment is not presently available.

Module C discusses peritoneal dialysis and describes current service issues in the province. Recommendations outlined on page 4 provide the basis for provision of enhanced peritoneal dialysis services. Research has indicated that when patients receive appropriate and comprehensive pre-dialysis information, there is a greater uptake of this modality. Currently 21% (n=73) of patients opt for peritoneal dialysis therapy at home versus 79% (n=267) currently accessing haemodialysis at an institutional or community based site. These figures do not include the three patients currently on haemodialysis at home.

The table below shows the number of people who were newly diagnosed with ESKD and required either haemodialysis or peritoneal dialysis between 1995 and 2000.

Table 3: Six year trend of newly diagnosed ESKD patients.

Catchment Area	Population (20 years +) 2001	1995	1996	1997	1998	1999	2000	Total
St. John's Area	145,544	24	34	33	36	42	34	203
Carbonear/Old Perlican Placentia/Whitbourne Area	39,175	17	14	17	8	12	19	87
Clarenville/Bonavista Area	39,254	3.5	4	2	6	8.5	6	30
Burin Area		1.5	2	3	3	3.5	2	15
Central East Area	31,621	7	13	8	12	5	3	48
Central West Area	46,221	6	8	11	7	8	9	49
Corner Brook/Deer Lake/Norris Point Area	62,420	10	8	12	11	14	14	69
Stephenville/Channel/ Port aux Basques Area		3	6	2	5	5	4	25

South Coast Area		1	3	2	3	1	1	11
Grenfell Area St. Anthony/Labrador Straits/Southeast Coast	12,558	3	2	4	3	3	2	17
Labrador Area	16,578	1	0	0	2	0	3	6
Total:	**393,371**	**77**	**94**	**94**	**96**	**102**	**97**	**560**

Areas for Consideration of a Haemodialysis Unit

In considering the establishment of haemodialysis services, the implications for each of these models must be examined and are outlined in Module D. Table three provides actual numbers of newly diagnosed ESKD patients who require dialysis and/or transplantation. Based on provincial trends to date, 20% of patients are expected to access transplant services (average of 26 patients for past 5 years), 20% may opt for peritoneal dialysis while 10% will not be medically stable enough for a haemodialysis satellite unit and will continue to require care at a hospital based site. The remaining 50% could access a satellite unit for an average time of five years.

Table 4: The following table represents an analysis of ESKD patients expected to access haemodialysis services in a satellite unit.

Area	**Total # of new ESKD Patient 1996-2000**	**Average Yearly Number**	**50% of Patients Considered to Access a Satellite Unit**	**Potential Patient Volume Over a 5 year period.**
Conception Bay North	70	14	7	35
Central East	41	8.2	4.1	21
Burin	13.5	2.7	1.4	7
Labrador	5	1	0.5	3
St. Anthony	14	2.8	1.4	7

In an effort to confirm these percentages, the actual numbers for the Clarenville site was analysed. There were 26 patients diagnosed with ESKD from this catchment area from 1996 to 2000 and based on the 50% trend, 13 patients would be expected to access the Clarenville satellite site. However, the actual number of patients accessing services over the past year was between four and six. Therefore, this estimated shortfall reflects a need, when planning for a satellite unit, to review demographic trends, options for people with ESKD, ages of patients and other debilitating diseases, etc. in order to more adequately assess catchment population.

The evaluations of the Stephenville and Clarenville sites noted that patient volumes have a direct cost impact. The costs at the Clarenville site, which had an average of five patients throughout the year, were 51% higher as compared to St. John's. This higher cost is primarily due to the need to maintain a minimum number of skilled staff even with a lower patient volume. Also, the resources required to set up and maintain a satellite unit regardless of patient volume are significant. Therefore, it is more efficient to maximize the capacity of a few satellite units than to open several within a geographic area. It is not economical, efficient or reasonable to operate two facilities within close proximity to one another. It is important to note that evaluations of Stephenville and Clarenville did not indicate a minimum number of patients which would make a unit viable, however the Committee supports a base of 10-12 patients as a minimal viable number. This minimum number is primarily based on staffing requirements and secondarily on cost.

Based on an analysis of current patient volumes, demographic information and evaluations of the pilot satellite units, the Conception Bay North and Central East areas are determined to be viable and are recommended as new satellite dialysis sites. Planning for the establishment of these units will be within the context of the Provincial Kidney Plan. Resources by the incentre unit need to be determined in this Plan. The Committee does not recommend moving forward with a satellite unit in Burin, St. Anthony or Labrador at this time.

Recommended Model for Haemodialysis Satellite Units

The Committee discussed both the community and institutional models and highlighted the Comparison of Models document by Panacea Research which indicated: "it is the opinion of the evaluators that with appropriate planning and resources, haemodialysis units have the potential to be effective in both hospital and community settings" (see Module F). The Committee agreed that based on the recommendations in the evaluation reports, the preferred model would be one that is located in the community but administered by a Regional Institutional Board. Location of the satellite unit within the community recognizes that patients must be medically stable and suitable for that particular environment. Placing the unit in a hospital could raise expectations and cause unstable patients to expect a full range of services. Hospital units in secondary sites such as Grand Falls-Windsor lack consistent coverage by a nephrologist and/or an internal medicine specialist with experience in dialysis and therefore cannot provide the specialized services on a consistent basis. In a non-hospital unit, nephrologist services could be provided at a distance with periodic visits and review of patients through information technology systems while having access to immediate medical back-up by telephone.

It will be vital to ensure proper education of patients/families, physicians and key stakeholders regarding the types of services that can be provided by satellite units. Administration by an institutional board is recommended primarily due to increased access to a larger pool of appropriate human resource personnel and other supports provided in the institutional sector as outlined in the Comparison of Models Report.

FRAMEWORK FOR THE DEVELOPMENT OF A PROVINCIAL KIDNEY PROGRAM

The Strategic Health Plan released in Fall 2002 outlines key challenges which affect the health and community services system. These challenges include the health status of the population, changing demographics, quality and accessibility of services, and sustainability of health services. The Strategic Health Plan also speaks to the challenge of increasing costs of the health and community services system, and the need to reorient our focus to that of wellness such that future generations will not be overburdened with increasing health care costs.

The Provincial Renal Advisory Committee has identified these challenges in the development of a provincial plan for kidney disease. The health status of the population of the Province has among the highest rate of circulatory diseases and diabetes in the country. These diseases often lead to chronic kidney disease and it is reasonable to think that prevention of these chronic diseases through positive lifestyle changes would lead to a reduction in growth of chronic kidney disease rates.

Coordination of planning across regions has been problematic, as illustrated by the complexity and weaknesses in the inter-board arrangements associated with the haemodialysis units in Grand-Falls-Windsor and Clarenville. For example, lines of responsibility for the quality-of care in the haemodialysis unit in Grand-Falls-Windsor were quite unclear during the times when a nephrologist was or was not available on site. Similarly, there have been differences of opinion between staff at the Eastern Region satellite unit in Clarenville and the in-centre program at the Health Care Corporation of St. John's about the definition of medically stable patients at the satellite site. The lack of provincial standards against which to resolve issues is problematic. The lack of inter-regional coordination has also led to economically disadvantageous contracting for equipment and disposables by regions with smaller volumes. A provincial approach to such purchases would lead to lower cost overall as a result of volume related discounting.

No individual agency in this Province has the mandate to plan or advocate for preventive programs, or the enhancement of evidence-based care for people with chronic kidney disease in primary and specialty practice. The small population base, and the very variable complement of health care providers within regions, strongly suggests the need for a provincial authority to oversee and address issues related to provision of specialized services for people with kidney disease. It would be preferable to have an agreed set of standards for kidney disease care and the implementation and monitoring of such standards will require a degree of cooperation and sharing of responsibilities across regions. Given the lack of expertise within some regions where specialized services may be delivered, it is not likely these issues can be handled successfully solely within the regional model of responsibility.

Other jurisdictions in Canada are taking a provincial approach to kidney disease care. For example, a plan for a provincially coordinated model of service planning, standard setting and oversight was developed for Nova Scotia and P.E.I in 1999. Manitoba's services for advanced kidney disease care are managed via a provincial program. Dialysis services in Alberta are handled by separate Southern and Northern Renal Programs, based in Calgary and Edmonton respectively. British Columbia has moved steadily in recent years to a coordinated kidney disease care model applied via the B.C. Renal Program and the B.C. Transplant Society. Considerable progress has consequently been made in the areas of standard setting, practice evaluation, quality improvement and service planning.

There have been provincial programs for organ procurement for transplantation and for provision of peritoneal dialysis. However, the lack of authority with a clear provincial mandate for haemodialysis, pre-dialysis care, post-transplant follow-up including the provision of subsidized immunosuppressive medications has hampered efforts to address regional needs for service development. This deficiency has been highlighted during the efforts to decentralize haemodialysis services to sites other than St. John's and Corner Brook. Regions that currently do not provide specialized care for kidney disease lack the internal expertise to address these needs. The recent division of responsibility for the peritoneal dialysis program raises the possibility of future inter-regional disparities in aspects of this care.

The evaluation of the Stephenville institutional - based satellite site and the Clarenville community - based satellite site showed that coordinating the efforts of the involved boards was challenging. For both sites, several informants noted difficulties in communication and decision-making. It is suggested that such problems could be ameliorated with the appointment of a full time Provincial Coordinator and a part time Medical Director who is a certified nephrologist. The Coordinator would be responsible for collecting, evaluating, and disseminating kidney disease data to inform decision making on issues related to all aspects of kidney disease and dialysis. The medical director/advisor could provide the expertise needed to offset the difficulties associated with miscommunication and misinformation between boards and facilities found in the evaluation of the pilot sites. The Coordinator could also facilitate provincial tenders for dialysis equipment and supplies translating into sizable cost savings to the province. Such an option would remove many of the challenges that have been revealed in the evaluations of the pilot sites. It is suspected that the magnitude of such savings would certainly be more than sufficient to fund the proposed positions.

The Provincial Renal Advisory Committee is fully supportive of this Provincial Model of coordinated services for kidney disease and supports the development of the Framework for a Provincial Kidney Program outlined in this document.

PLAN OF ACTION

An important first step in the development of a Provincial Kidney Program is the implementation of a Provincial Coordinator with the necessary skill set to develop standards, policies and guidelines in accordance with the Framework. The Coordinator will engage Regional Board stakeholders and the Department of Health and Community Services in the planning and delivery of kidney disease care and ensure a focus on the prevention of kidney disease as an explicit objective. A Medical Director who is a certified nephrologist is essential to provide consistent clinical expertise to the Program.

A vital component shall be to ensure proper education of patients/families, physicians, Regional and Provincial authorities and other key stakeholders regarding the expectation of services in all aspects of kidney disease care. This will be essential in areas where current services exist and in the development of new modalities of care, especially for existing and new satellite units.

The development of a Provincial Evaluation Implementation Committee will ensure effective and quality services and will have the mandate to evaluate compliance with developed standards including all aspects of care. This Committee will also have the mandate to intervene via existing Regional and Provincial authorities in situations where standards are not being met.

In order to establish satellite dialysis units in Conception Bay North and Central East, a phased-in approach is recommended. This requires planning within the context of the Provincial Kidney Program and will require the Coordinator to engage key stakeholders in working groups to ensure that planning is in keeping with established standards, policies and guidelines. This plan would also include determining the resources needed centrally by the in-centre institution to effectively manage the satellite unit.

CONCLUSION

Patients with kidney disease represent a growing segment of our health care system as the incidence of ESKD has steadily increased over the past decade. Efforts to prevent kidney disease or to improve people's quality of life through transplantation are preferable to dialysis however, the need for dialysis will continue to exist until significant progress is made in prevention and lifestyle areas.

The Provincial Renal Advisory Committee encourages the Department of Health and Community Services to sanction the recommendations put forward in this report and move forward with the plan of action to develop a coordinated Provincial Kidney Program.

APPENDIX I

GLOSSARY OF TERMS

Anemia - also commonly known as "low blood", implies a deficiency in blood of red cells and the protein hemoglobin that is responsible for carrying oxygen from the lungs to tissues.

Atherosclerosis - a disease process in the walls of arteries that weakens and may narrow the vessels. This disease process underlies many heart attacks, strokes and the need to amputate legs due to failure of circulation.

Biomedical Technologist - a person responsible for the maintenance and repair of dialysis machines both in hospital and home. The technologist is also responsible for assisting with intraoperative dialysis procedures.

Chronic Kidney Disease - a progressive disease which interferes with the kidney's ability to remove waste from the body. Kidney disease has many causes however diabetes and high blood pressure are common causes.

Creatinine - waste substance that is produced when muscles are used. Measuring the creatinine level in the blood gives an indication of how well, or poorly, the kidneys are working. As kidney disease progresses, the level of creatinine in the blood increases.

Determinants of Health - interacting factors that contribute to health including income status, social and physical environments, education, personal health practices, health services, culture, gender, etc.

Dialysis - treatment for kidney failure that removes waste and water from the blood. It cleans the blood either by passing it through an artificial kidney machine or by filtering it inside the abdomen. Dialysis may be used as a temporary measure or long term when kidneys have failed.

End Stage Kidney Disease (ESKD) - Generally irreversible state where the kidney function is less than 10-15 percent and renal replacement therapy, dialysis or transplantation, is required to sustain life.

Haemodialysis - a process which removes waste and water from the blood by passing blood through an artificial kidney machine.

In Centre Unit - a hospital based haemodialysis unit.

Kidney Foundation of Canada - a national volunteer organization dedicated to improving the health and quality of life of people living with kidney disease.

Kidney Transplant - provision of organ function by transplantation of an organ from another individual into an individual with end stage organ failure. Kidneys for transplantation are obtained both from living and cadaveric (deceased) donors. A kidney transplant is considered the best available treatment for ESKD.

Medical Internist - a physician who specializes in the prevention, diagnosis and non-surgical treatment of diseases affecting the internal organs of the body.

Nephrologist - a physician who specializes in the study and treatment of diseases of the kidney.

Peritoneal Dialysis - a process which removes waste and water from the blood by filtering it inside the abdomen.

Population Health - an approach to health that aims to improve the health of the entire population and to reduce health inequities among population groups using the determinants of health factors.

Primary Health Care - The first level of contact people have with the health and community services system which promotes a team-based, interdisciplinary approach to service delivery where physicians, nurses and other health care professionals cooperate in providing services.

Strategic Health Plan - Released by the Minister of Health and Community Services in the Fall of 2002 which lays out a framework for the development of sustainable appropriate health services for the Province.

Satellite Unit - a decentralized haemodialysis unit primarily providing services closer to the patient's place of residence. This unit depends on an in-centre site for some service provision.

Skill Mix - the appropriate mix of different health care providers who provide safe, quality patient care.

Uremia - a term applied to the consequences of kidney failure where known and unknown substances build up in the body leading to the adverse health effects in this condition.

APPENDIX II

TERMS OF REFERENCE
PROVINCIAL RENAL ADVISORY COMMITTEE

Membership

The Provincial Renal Advisory Committee will be representative of health organizations, service providers, the Department of Health and Community Services, and the Kidney Foundation. (The Kidney Foundation member may also serve as a consumer representative.)

Committee Members

- Department of Health & Community Services
- Nephrologist
- Kidney Foundation
- Western Dialysis Services
- Central Dialysis Services
- Eastern Health & Community Services Satellite Dialysis Unit Pilot Project
- Social Worker, Health Care Corporation Dialysis Program
- Program Manager and Program Director, Health Care Corporation Dialysis Program
- General Practitioner, NLMA
- Organ Procurement Program

Structure

The Provincial Renal Advisory Committee will have a chair appointed by the Minister of Health and Community Services. The Advisory Committee may establish working sub-committees with chairs selected from the general membership.

Meetings

The Advisory Committee will meet a minimum of quarterly and more frequently as required.

Reporting Relationship

The Advisory Committee will report to the Minister of Health and Community Services and will submit a written annual report at the end of each fiscal year.

Mandate

The mandate of the Advisory Committee is to advise the Department of Health and Community Services on issues related to the planning, development, implementation and evaluation of renal services for the province.

Roles and Responsibilities

The Advisory Committee will be responsible for:

- reviewing the current renal services and program components in the province in order to identify existing and potential gaps in service delivery;
- developing a framework for the provision of a comprehensive, provincial renal program focusing on disease prevention, health promotion, and treatment options at the primary, secondary and tertiary levels, which includes:
    - identifying service requirements that reflect the continuum of care
    - reviewing and making recommendations regarding development, expansion and restructuring of renal replacement services for the province
    - identifying strategies to improve health promotion and prevention of renal failure;
- ensuring liaison between and among the various service components and other related organizations eg. transplantation, diabetes education/strategies and organ donation program;
- identifying mechanisms to address operational issues within regional board structures;
- establishing mechanisms for communications and information dissemination among service delivery sites, regional health boards, health professionals, consumers and government;
- developing standards for the provision of renal services in the province, which includes developing:
    - a standard costing model for comparative purposes
    - provincial program standards, policies and procedures for consistent delivery of services
    - standards related to staffing, space and physical facility requirements for the provision of dialysis
    - a strategy for the acquisition of equipment and supplies to facilitate cost effectiveness and ease of patient and staff mobility;
- developing a mechanism for collecting and analyzing data on existing services for quality improvement purposes;
- developing a mechanism for collecting data for the purpose of planning for renal services; and
- identifying a human resource plan.

December 2002

APPENDIX III

PROVINCIAL RENAL ADVISORY COMMITTEE MEMBERS

Dr. Brendan Barrett (Chairperson)
Nephrologist
Associate Professor of Medicine (Nephrology)
Health Sciences Centre

Dr. Ed Hunt
Medical Consultant
Medical Services Branch
Department of Health and Community Services

Mr. Derek Penney
Budget Officer
Financial Services, Support Services Branch
Department of Health and Community Services

Mr. Morgan Pond
Policy Development Specialist (Adult)
Policy Development, Policy and Program Planning Branch
Department of Health and Community Services

Ms. Beverly Griffiths
(Replacing **Ms. Eva Laing**)
Regional Consultant
Board Services Division
Department of Health and Community Services

Ms. Fay Matthews
Chief Executive Officer
Health and Community Services - Eastern
Clarenville Satellite Dialysis Unit

Dr. Stephen Murphy
Nephrologist
Medical Consultants of Western Newfoundland
Corner Brook

Ms. Christine Chadderton
Patient Care Coordinator
Western Memorial Regional Hospital

Ms. Jill Martin
Team Leader, Dialysis Services
Central West Health Corporation
Grand Falls-Windsor

Ms. Dallas Mifflin
Kidney Foundation Representative

Mr. Max Bishop
Program Coordinator
Organ Donor Program

Ms. Luanne Kinsella
Program Director
Medicine Program
Health Care Corporation of St. John's

Ms. Cheryl Harding
Division Manager, Dialysis Services
Health Care Corporation of St. John's

Dr. Jeremy Hillyard
Medical Officer of Health
Charles S. Curtis Memorial Hospital
St. Anthony

APPENDIX IV

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*For ease of reference, Bibliographies are attached to Modules B and C.

Module A

Regional Demographics

Regional Demographics

In determining the need for renal services in various areas throughout the province, changes in population need to be examined. While data from Canadian Institute for Health Information indicated that half of new patients with ESKD are over 65 years of age, it should be noted that in this province, the average age of people presently receiving dialysis treatments is approximately 60. When considering models of service, it must be recognized that support at the community level for home dialysis may be limited as spouses of patients are aging and the younger age group is declining, due primarily to outmigration. For the purpose of this document, the province is divided according to Health and Community Services Regions.

The table below shows the 2001 population of selected age cohorts by Health & Community Services Regions and projections for 2016.

Newfoundland and Labrador Population Projections by Health Board, Medium Scenario

	Health and Community Services St. John's	Health and Community Services Eastern	Health and Community Services Central	Health and Community Services Western	Grenfell Regional Health Services Board	Health Labrador Corporation	Total
2001							
0 - 4	8884	4976	4494	3873	786	1593	24603
5 - 19	35902	22295	19633	16291	3431	5669	103217
20-44	72001	39269	36152	28572	6291	9697	191982
45-64	45994	30549	27721	23006	4336	5773	137381
65+	20486	15210	14430	10843	1931	1108	64017
Total	**183267**	**112299**	**102430**	**82585**	**16775**	**23840**	**521200**
2016							
0 - 4	8320	3248	3036	2775	505	1494	19377
5 - 19	26963	12866	12077	10527	1879	4579	68894
20-44	65285	26656	25877	20646	4132	9024	151622
45-64	60321	32893	32958	25743	5263	6941	164125
65+	32256	19898	21299	16997	3381	2546	96376
Total	**193145**	**95561**	**95247**	**76688**	**15160**	**24584**	**500394**
% change 2001-2016							
0 - 4	-6.3	-34.7	-32.4	-28.4	-35.8	-6.2	-21.2
5 - 19	-24.9	-42.3	-38.5	-35.4	-45.2	-19.2	-33.3
20-44	-9.3	-32.1	-28.4	-27.7	-34.3	-6.9	-21
45-64	31.1	7.7	18.9	11.9	21.4	20.2	19.5
65+	57.5	30.8	47.6	56.8	75.1	129.8	50.5
Total	**5.4**	**-14.9**	**-7**	**-7.1**	**-9.6**	**3.1**	**-4**

Health and Community Services - St. John's Region

Since 1991, the population of the St. John's Region has decreased slightly, with the current population being 183,267 (1991:186,616) and almost 95% residing in St. John's. It is anticipated however that the population of the Region will grow by approximately 10,000 by 2016 to 193,145. Overall outmigration in the Region has been low, the birth rate is the second highest in the Province and the mortality rate has not increased since 1991. Unlike most regions, there has been a net inmigration between the ages of 5 and 19 and 65 and 79. The St. John's Region is one of the two regions in the Province where the overall population is predicted to increase over the next 15 years. Another interesting element of the population is the age distribution. In the St. John's Region, there is a marginally lower proportion of individuals aged 65 and over than for the province as a whole, i.e., 11.2% (21,772) compared to 12.3%. This percentage is expected to increase to 17.7% over the next 15 years. Demographic projections for the age group 20 to 44 years indicates a decrease of 9.5, the second lowest in the province over the next 15 years, while the age group 45 to 64 is expected to increase by 31.2% (the highest in the province).

From 1986 to 1997, causes of death for endocrine disease including diabetes was fairly constant. According to the National Population Health Survey, the incidence of high blood in St. John's Region was the lowest for the province at 15% compared to the provincial rate of 19%.

The furthest distance people have to travel for services including Haemodialysis is the 2 ½ hour drive from Trepassey.

Health and Community Services - Eastern Region

Since 1991, the population of the Eastern Region has decreased from 129,317 to its current population of 112,299 and it is anticipated that this will decrease to 95,561 by 2016. Within this region, there are two institutional boards which provide services to the population, i.e., Avalon Health Care Institutions Board and Peninsulas Health Care Corporation.

Since 1991, the population with the Avalon Health Care Institutions Board has decreased from 58,322 to 51,515 in 2001. It is projected that this will decrease to 41,685 by 2016. Approximately 55% of this population live in the Conception Bay North area. Statistics Canada shows the decease in population in this area from 1996 to 2001 was slightly higher than the provincial average, i.e., 8.1% compared to 7.0%. Looking at the age distribution, the area presently has a higher proportion of individuals aged 65 years and over than for the Province as a whole, i.e., 14% compared to 12.3%. It is projected that by 2016, there will be a 24.3% increase (7464 to 9280). This increase however is significantly lower than the projections for other catchment areas. Demographic projections for this region indicate a decrease of 35.1% of people ages 20 to 44 and a decrease of 0.9 in the age group 45 to 64 by 2016.

Since 1991, the population within the Peninsulas Health Care Corporation catchment area has decreased from 61,105 in 1991 to 51,793 in 2001. It is projected that this will decrease to 44,408 by

2016. The major centres of Marystown, Burin, Grand Bank, Clarenville and Bonavista comprise approximately 38% of the population. The decrease in population in this area from 1996 to 2001 is higher than the provincial average, i.e., 11.3% compared to 7%. Looking at the age distribution in this area, the proportion of individuals 65 years and over is comparable to the province as a whole, i.e., 12.6% compared to 12.3%. This trend is likely to continue to 2016 with projections of a 33.4% increase (6554 to 8743). Demographic projections for this area indicate a decrease of 32.8% in the age group 20-44 and an increase of 12.3% in the age group from 45 to 64 by 2016.

Over the 12 year period from 1986 to 1997, the death rate in the Eastern Region due to endocrine disease including diabetes was 68 per 100,000 compared to 70 per 100,000 for the province. According to the Adult Health Survey in 2001, the percentage of people reporting having high blood pressure was 19%, which is comparable to the provincial rate.

People from Clarenville/Bonavista catchment areas currently receive haemodialysis services in Clarenville and patients from all other areas receive services in St. John's.

Health and Community Services - Central Region

Since 1991, the population of the Central Health and Community Services Region has decreased from 120,238 to the current population of 102,430. It is projected that this will decrease to 95,247 by 2016. Thirty-two percent (32%) of residents live in Gander and Grand Falls-Windsor. Statistics Canada shows that the decrease in population in Central Newfoundland from 1996 to 2001 was higher than the provincial average, i.e., 18% compared to 7.0%.

Within this region, there are two institutional boards which provide services to the population, i.e., Central East Health Care Institutions Board and Central West Health Corporation.

Looking at the age distribution, it is interesting to note that in the Central Region there is a slightly higher proportion of individuals aged 65 and over than for the Province as a whole and this trend is predicted to increase over the next 15 years. Population information by age and gender for 2001 provided by Economic Research and Analysis Division of Department of Finance was reviewed for Central Region. When looking at this population breakdown for the board catchment areas, there were differences noted. Over the 10 year period from 1991 to 2001, the 60 to 64 age group showed an 7.4% increase in Central East while there was a 11.7% increase in Central West. The age group from 65 to 69 years showed a decrease of 2% in Central East catchment area, while the catchment area for Central West showed a 14% increase. In the 70 to 74 age group, there was an increase of 5.5% in the Central East catchment area while there was a 11% increase in the Central West catchment area. In the 75 to 80 age group, there was an increase of 5% in Central East catchment area compared to a 25.7% increase in Central West catchment area. The percentage change in the younger age groups in both catchment areas were comparable. There was a decrease of 29% in the 20 to 39 age group in Central East and 29.3% in Central West. In the 40 to 60 age group, there was an increase of 22.4% in Central East and 20.4% in Central West. Demographic projections indicate an increase of 40.6% in the age group 65 and over in the Central East catchment area by 2016 and a 52.5% in this age group in the Central West catchment area. A decrease of 30.2% is projected in Central East for the 20 to 44 age group and an increase of 14.8% in the 45 to 64 age group. For the Central West catchment area, a decrease of 27.2% in the 20 to 44 age group is projected and an increase of 21.6% in the 45 to 64 age group.

Over the 12 year period from 1986 to 1997, the death rate in Central due to endocrine disease including diabetes was the highest in the province (88 per 100,000 compared to 70 per 100,000 for the province). According to the Newfoundland and Labrador Adult Health Survey, 2001, the percentage of people reporting diabetes in the Central Region was higher than other regions (i.e.) 10% compared to 6% in St. John's, 8% in Eastern and 7% in Western. The percentage of people who reported having high blood pressure was also higher than other regions (i.e.) 22% compared to 15% in St. John's, 19% in Eastern and 20% in Western.

Health & Community Services - Western Region

Since 1991, the population within the region has decreased from 96,278 to 82,585 in 2001 and is expected to decrease to 76,688 by 2016. Within this region, 67% of residents live in Corner Brook, Stephenville, Channel Port aux Basques, Pasadena and Deer Lake. Corner Brook alone has over 28% of the Region's population. The decrease in population in this area from the 1996 census to 2001 census is higher than the provincial average, i.e., 10.3% compared to 7%.

Looking at the age distribution in this area, the proportion of individuals 65 years and over is marginally higher than the province as a whole, i.e., 13.1% compared to 12.3%. The increase in this age group is projected to increase by 56% over the next 15 years, i.e., 10,843 to 16,900. Demographic projections for this region indicate a decrease of 27.7% in the 20 to 44 year olds over the next 15 years and an increase of 11.9 in the 45-64 year olds.

Over the 12 year period from 1986 to 1997, the death rate in the Western Region due to endocrine disease including diabetes was lower than for the province as a whole 51 per 100,000 population compared to 70 per 100,000 population. The percentage of people reporting high blood pressure was slightly higher than for the province, 20% compared to 19%.

Grenfell Region

Grenfell Regional Health Services Board is an integrated Board which provides full institutional and community health services to the region. Since 1991, the population of Grenfell Region has decreased from 20,613 to its current population of 16,775 and it is anticipated that this will decrease to 15,160 by 2016. Seventy-seven percent of the population live on the island portion of the Region while 23% live on coastal Labrador. When looking at the reasons for the population decline in the province, Grenfell region has been the hardest hit by outmigration. There were noticeably higher losses than the Province as a whole in all age categories, except for the ages of 70 and 74 and the over 80 age group. Another interesting element of the population breakdown is the age distribution. In the Grenfell region, there is currently a slightly lower proportion of individuals age 65 and over than for the Province as a whole, i.e., 11% compared to 12.3%, (1931 people). This trend, however, is expected to reverse over the next 15 years with a projection of a 75.1% increase by 2016 (to 3381 people). Demographic projections for this region indicate a decrease of 34.3% in the age group 20-44 years and an increase of 21.4% in the 45 to 64 age group by 2016.

Communities in this region are less than one hours drive, i.e. average range from 18 to 35 minutes from the community health centre in their geographic area. The exception to this is in Southern Labrador where some communities are up to 1½ hours from the centre in Forteau. To reach St. Anthony Hospital, the furthest distance for travel on the island portion is approximately 2 hours. Travel for Coastal Labrador is 30 minutes by boat or air. At present, people from Grenfell Region access haemodialysis services at St. John's or Corner Brook.

Health Labrador Corporation

Health Labrador Corporation is an integrated Board which provides full institutional and community health services to the region. Since 1991, the population of the Labrador Region has decreased slightly from 26,463 to its current population of 23,840 and unlike any other region of the Province, it is anticipated that the population will increase to 24,584 by 2016. Eighty percent of the residents in this region live in Labrador City and Happy Valley-Goose Bay.

The reasons for the population decline in the Labrador Region are slightly different than for the Province as a whole, being more heavily tied to outmigration and less so to birth rates and mortality rates. The Labrador Region has been the second hardest hit region, overall, by outmigration, with noticeably higher losses than the Province as a whole in many age categories. Unlike most other regions, the net outmigration in the Labrador Region is largest between the ages of 15 and 29. There have also been high levels of outmigration between the ages of 50 and 64. This is typical of a region where individuals relocate from other regions or provinces for work and leave again once they conclude their employment.

The Labrador Region is also unique in that it is the only Region outside of St. John's where overall population growth is predicted in the next 15 years. This is due to an anticipated slowing of outmigration, ongoing inmigration necessary to fill the vast number of new and continuing trades positions in the Region, and higher fertility rates and lower mortality rates than other areas of the Province.

Another interesting element of the population breakdown is the age distribution. The Labrador Region is currently younger than other regions of the Province with less than 5% of its residents being over 65 years, i.e., 1108. While the proportion of individuals over the age of 65 is expected to grow, it will continue to be significantly lower than the rest of the province.

From 1986 to 1997, the death rate due to endocrine disease including diabetes in Labrador remained the lowest in the province (31 per 100,000 population compared to 70 per 100,000 for the province as a whole). This is not surprising given that the death rate in the Region remains the lowest in the

Province and is tied to the low numbers of individuals over the age of 50. Unfortunately, rates for high blood pressure were not available for this region from the National Population Health Survey as the numbers were too small for calculation.

Aboriginal Health in Labrador is a concern when looking at the overall health of the region. The diabetes rate in many aboriginal cultures in Canada is three to five times higher than that of the general Canadian population especially type II diabetes occurring in younger children. Therefore it is anticipated there will be an increased need for dialysis therapies in this region.

Module B

Prevention and Treatment of Chronic Progressive Kidney Disease

Prevention and Treatment of Chronic Progressive Kidney Disease

1. Summary
2. The rationale for focusing on chronic kidney disease.
3. How to prevent kidney disease progression and related cardiovascular events in established CKD.
4. People with CKD are currently often under-treated.
5. Organizing care for people with CKD.
6. Intensified care for CKD may be economically attractive.
7. Issues in implementation a change in care patterns for CKD.
8. Care for advanced CKD prior to ESKD.

1. Summary

The medical, social and financial burden posed by end-stage kidney disease (ESKD) is large and growing rapidly. People generally reach ESKD as a result of chronic progressive kidney disease (CKD). Many of the underlying diseases causing or aggravating kidney failure, such as diabetes and high blood pressure, are amenable to primary prevention by population and individually-based interventions. The progress of advancing kidney disease can be slowed in many cases and is also associated with several treatable complications such as anemia, parathyroid and bone disease, which if poorly managed reduce the length or quality of life. In addition, there are strong links between CKD and cardio-vascular diseases. Many people with less advanced CKD will die or suffer complications of cardiovascular disease before reaching ESKD. Efficacious interventions, such as lowering blood pressure and treating dyslipidemia, can substantially reduce the progression of both kidney and cardiovascular disease. Careful management of these complex and inter-related diseases and risk factors requires detailed longitudinal and focused care which does not seem to be optimally delivered by health service practitioners organized in traditional ways. A disease management approach involving the chronic care model offers promise in this setting, but requires further study of clinical and economic impact. Advanced CKD prior to dialysis requires specialized multi-disciplinary care. Timely involvement of specialized teams and reasonable access is needed to these services across the province. Recommendations are made to enhance the care of those with CKD in the province.

2. The rationale for focusing on chronic kidney disease.

a) End-stage kidney disease (ESKD) is a huge, growing and costly problem.

Canadian national registry data show a compound annual growth of 7.3% in new ESKD cases (1). Preliminary statistics indicate over 14,500 Canadians were on dialysis in 2000. 20,000 are projected by 2005 (2). Similar trends are evident in the United States. ESKD significantly reduces survival, and quality of life (1). Indeed a recent analysis of U.S. data indicates that ESKD leads to more lost life years than prostate cancer in men, and almost as many as breast cancer in black women (3). The elderly and diabetics are the fastest growing segments of the ESKD population. Substantial co-morbidity is often present at the onset of ESKD. Cardiovascular disease kills 35 to 52% (greatest in the elderly and diabetics) of Canadians with ESKD (1). Cardiovascular disease is already well established by onset of ESKD. Symptomatic ischemic heart disease was present in 38% and heart failure in 35% of Canadians at first dialysis (4). Only 16% of new dialysis patients have normal hearts, with concentric left ventricular hypertrophy present in 41% and systolic failure in 16% (5). Existing and projected shortages of nephrologists, renal nurses and other professionals may make it difficult to comprehensively meet the health care needs of the growing dialysis population. Transplantation is a medically and economically superior treatment for ESKD (6), but shortage of organs and medical suitability criteria mean that many patients will be dependent on dialysis. The financial cost of caring for patients on dialysis is very high, with direct annual health care costs ranging from about $32,570 for those on home haemodialysis, to $88,585 for those on hospital-based haemodialysis (7). U.S. data suggest that the cost of care for ESKD far exceeds that for prostate or colorectal cancer in men, and breast cancer in black women (3).

b) Much chronic kidney disease could be prevented altogether

Diabetic nephropathy is the single most common disease leading to ESKD. The relative contribution of diabetes to the treated ESKD population has increased over the past decade. This is partly due to an increasing consideration of dialysis and transplantation as appropriate therapies for those with diabetes and kidney failure. However, there has also been a steady increase in the prevalence of diabetes itself. This in turn is largely due to the impact of caloric excess and under activity on a background of genes predisposing to the condition. Several studies have demonstrated that lifestyle related changes in diet and exercise patterns are capable of slowing the decline in glucose tolerance and emergence of diabetes in populations at risk. This evidence base suggests the possibility of preventing some ESKD due to diabetes by preventing or delaying the onset of diabetes itself. Hypertension/vascular disease is also a major and growing contributor to the burden of ESKD. As with diabetes, these conditions are affected by lifestyle choices on a background of complex genetic risk. Together, diabetes and hypertension/vascular disease currently account for about half of all ESKD and are responsible for much of the steady growth in the size of the problem.

Primary prevention of kidney disease does not currently require any specific program other than those that might be aimed at precursor conditions. Reducing the burden of CKD would be just one potential benefit of such programs. Cardiovascular disease prevention would be another major outcome goal. Strategies to prevent diabetes, and likewise hypertension, can be focused on individuals at risk, or may be more broadly based in a population. Frameworks for such prevention have been proposed by a number of organizations in North America and Europe at least. Multiple approaches, carefully co-ordinated and targeting populations, communities and individuals are likely to yield the best results. These prevention strategies will need to involve many areas of life outside the health care sector. For example, policies aimed at the food industries, municipal planning and building codes, as well as programs targeting healthy body weight, activity levels and nutrition for individuals will all be needed. Furthermore, programs will need to be delivered in diverse settings such as schools, community settings and workplaces in order to reach target populations. The Newfoundland and Labrador Heart Health Program is one existing initiative that meets some of these needs.

c) The implications of existing Chronic Kidney Disease (CKD)

ESKD mainly results from progressive CKD, providing an opportunity to prevent ESKD and cardiovascular events (1,8). CKD was present in about 8% of the Framingham population, rising to 20% in the elderly (9). NHANES III data showed serum creatinine above the 99th percentile for healthy young adults in 3% of the U.S. population (10). Prevalence estimates are sensitive to the definitions and methods used to identify CKD (11-13). In a further analysis of adult non-diabetics in the NHANES III dataset, the prevalence of GFR $< 60\text{ml/min/}1.73\text{m}^2$ (by MDRD equation 7) was 13%, and by Cockroft-Gault formula 14% (12). These prevalence estimates may be somewhat artificially increased by the lack of standardization of serum creatinine measurement between laboratories and by the impact of within-person measurement error resulting from reliance on a single serum creatinine measurement (13). Nevertheless CKD is commonly unrecognized as serum creatinine is often in the "normal" range even when renal function is significantly impaired, especially in women and smaller persons (14,15). A serum creatinine as low as 104 μmol/L is quite predictive of a GFR < 60 mls/min/1.73m^2 in women (16). Hypertension, diabetes, and cardiac disease are associated with a higher prevalence of CKD (9-11). It is currently unknown how much of the growth in ESKD is due to growth in the prevalence of CKD (17), as opposed to a drop in competing risks (18), but elevated serum creatinine and proteinuria are strongly associated with future risk of ESKD in the general population (19,20).

CKD may progress after the initial cause has been removed (21). However, there are limited data on the natural history of CKD in unselected populations. Two thirds of normal elderly lose glomerular filtration rate (GFR), at an average of 0.75 ml/min/yr (22). A retrospective analysis of a Veterans Administration cohort with hypercreatinemia found increasingly elevated serum creatinine over 4 years in 49% of subjects with initial values in the range 160-267 μmol/L (23). Between 4 and 7.7% of subjects in the same cohort reached ESKD, with the lower rate in those with initial creatinine in the 125-150 μmol/L range (23). One third of hypertensive males lose renal function over 7 years (24). It has been estimated that 5% of hypertensives with elevated creatinine will require dialysis (25). Of a large group with CKD of various causes in a clinical trial, 85% suffered loss of GFR at an average of 4 ml/min/year (26). Finally, overt diabetic nephropathy may progress at 10-12 ml/min/yr if hypertension is untreated (27). Persistent proteinuria (20,28-31) and higher blood pressure, especially systolic (32-40) are associated with more rapid loss of GFR. Progressive CKD can be recognized by serial measurement of serum creatinine over time. Significant day-to-day variation complicates identification of trends (13,14,28). Calculating creatinine clearance or GFR is necessary to properly assess renal function and can be done from serum creatinine and demographic, anthropometric and other data (41,42). The Cockroft-Gault formula gives a reasonable estimate when the GFR is not very low (41). More recent formulae derived from data in the MDRD study, although more complex and difficult to use in practice, may be more accurate (42). Serum creatinine > 137 μmol/L in men and > 104 in women has good predictive accuracy for a GFR < 60 mls/min/1.73m^2 (16).

While it is thus possible to identify people with CKD, population screening is not yet recommended as the natural history of mildly reduced kidney function in unselected elderly people in the general population is not understood clearly enough at present. Clearly most do not progress to ESKD and therefore therapies aimed at avoiding this outcome would not be universally necessary.

However, even if CKD does not always lead to ESKD, there is still a concern that CKD identifies a population at much higher than average cardiovascular risk. A number of traditional (e.g hypertension, dyslipidemia, smoking) cardiovascular risk factors are seen to associate with CKD and their prevalence and severity change as kidney function declines (43,44). In addition, other factors such as hyperhomocystinemia, abnormalities of mineral metabolism, parathyroid function and a microinflammatory state may become more prevalent and have pathogenetic relevance as CKD progresses (45). In nephrology clinics, symptomatic heart disease prevalence ranged from 24 to 45.6 %, being higher at lower levels of kidney function (46). Elevated creatinine associates with a greater prevalence of cardiovascular disease in the general population (47,48), and a higher risk of vascular morbidity and death in hypertensive patients (49-52). Recent epidemiologic analyses may differ in their conclusions about whether CKD independently contributes to the risk of cardiovascular mortality (48,53), but they agree that CKD is a marker of high cardiovascular risk. Proteinuria is another independent risk factor for vascular events and death (54-58). It is presently unclear how much of the association between kidney and vascular disease results from: 1) vascular disease causing kidney failure; 2) kidney failure causing vascular disease, or 3) common underlying factors promoting the progression of kidney and cardio-vascular disease. It is likely that each of these mechanisms apply. For example, hypertension may cause and result from kidney disease and is a well known risk factor for heart disease and stroke. Renal anemia has been associated with cardiomyopathy and symptomatic heart failure (59,60). Proteinuria, including microalbuminuria, may result from renal micro-vascular injury, has been associated with endothelial dysfunction (61-63) and aspects of the "metabolic syndrome" including hypertension, insulin resistance/glucose intolerance, and dyslipidemia (64,65). Dyslipidemia has been associated with more progressive kidney disease (66,67) and is a known risk factor for cardiovascular events (68). Vascular calcification seen in CKD, results from active processes in the vascular wall (69), and may contribute to adverse cardiovascular outcome (70). These links along with the fact that approaches to improving cardiovascular and kidney outcomes overlap, have led to recent trials focusing on both kidney and cardiovascular event reduction (71,72).

Intervention in those with CKD is appropriate therefore earlier in the disease course, as many with CKD will die or suffer cardiovascular events before they reach ESKD. In addition advanced cardiac disease may not be correctable as evidenced by trials of anemia correction in patients on dialysis (73,74). By contrast those with normal ventricular volume did not dilate when the hemoglobin was normalized (74). Trials of anemia prevention in CKD are ongoing.

3. How to prevent kidney disease progression and related cardiovascular events in established CKD.

Several efficacious therapies already exist for established chronic kidney and cardiac disease.

a) *Lowering blood pressure* to <130/80 mmHg in CKD slows kidney disease progression (37,75-79). Those with more than 1 g/24 hours proteinuria benefit from even lower blood pressure (<125/75) (37). Lowering blood pressure reduces mortality in those at risk for cardiovascular events, including diabetics (77,80-82). Achieving low pressures usually requires between 3 and 4 different medications.

b) *Renin-angiotensin system interruption* by ACE inhibition (ACEi) reduces progression of CKD, proteinuria, and regresses LVH (83-86). ACEi reduce cardiovascular morbidity and death in CKD, as in those with normal GFR (49). ARBs also reduce ESKD, delay death, and reduce hospitalization for heart failure in type 2 diabetics with nephropathy (71,72).

c) *Treating dyslipidemia* reduces cardiovascular events and delays death (68,87-89). Benefits are at least as large in those with CKD (89,90). It is recommended that those with CKD be treated as for secondary prevention (91).

d) *Beta-blockade* is indicated for angina (92) and reduces morbidity and mortality in heart failure (93,94) and post myocardial infarction (95).

e) *Aspirin* prevents atherothrombotic events in patients at high risk of vascular events (96,97), and has a role in primary prevention in diabetics (77,97).

f) *Controlling diabetes* has beneficial effects on at least early microvascular disease (98,99). Metformin showed benefit for macrovascular disease in obese type 2 diabetics (100), but is contraindicated in CKD.

g) *Smoking cessation* reduces cardiovascular risk (101), may slow CKD progression (102-104), improves quality of life (105), may require intense intervention for maximal effect (106), but can be assisted by nursing intervention (107)

h) *Restricting dietary protein* has a limited effect in slowing CKD progression (108-110).

i) *Treating renal anemia* to a hemoglobin of 110-120 g/L improves quality of life, decreases hospitalization, and may improve LVH (111-116). Full normalization of hemoglobin does not seem to confer more benefit in dialysis patients with symptomatic cardiac disease (73).

j) *Control of calcium and phosphate metabolism* by dietary phosphate restriction, phosphate binders and activated vitamin D prevents some renal bone disease and severe secondary hyperparathyroidism (117,118). Care is required to avoid aggravating extraosseous calcification and causing adynamic bone disease (70,119,120).

While it is good that so many efficacious therapy options exist for this population with complex care needs, this in itself brings challenges in delivering care to those who may benefit.

4. People with CKD are currently often under-treated.

Current management of CKD is sub-optimal. CKD is under-recognized, due partly to the non-linear relationship between serum creatinine and GFR (14,15). High blood pressure is poorly controlled generally (121), and under-treatment is common in those with CKD (10), despite evidence that blood pressure can be safely and effectively lowered in CKD by combinations of anti-hypertensives (78). Patients with diabetes are inconsistently screened for early nephropathy (122,123). Patients with hypertension or diabetes often do not have serum creatinine checked in primary care (124). Canadians attending nephrology offices with CKD were commonly under treated with regard to blood pressure, lipid control, and aspirin (46). Less than half the CKD patients in a US HMO, diabetics included, were given ACE inhibitors and renal anemia was under-treated (125). Involvement of nephrology teams, only when CKD is already advanced has been associated with greater morbidity, mortality and cost (126-135). A multiple risk factor intervention approach in CKD has been suggested (136,137). A recently completed randomized trial of a specialized clinic focusing on intensified multiple risk factor intervention versus usual care, showed clearly improved microvascular disease in diabetics within 4 years (138). Of comparable value was the finding that on further follow-up to an average of 7.8 years, the intensive, target driven multiple intervention group had a significantly lower risk of major cardiovascular events as well (hazard ratio 0.47, 95% CI 0.24-0.73) (138a). Similar benefits of clinic delivered multiple intervention were seen in a before-after study of diabetics with more advanced CKD (139). In a recent survey, almost 80% of people with CKD attending a pre-dialysis clinic expressed a willingness to consider a strict diet, taking up to 6 extra medications a day, and six extra clinic visits a year, if this would delay the onset of ESKD by even a few weeks (140). Protocol guided care, co-ordinated by knowledgeable professionals focusing on disease management and prevention may offer the best opportunity to maximize uptake of efficacious therapies for people with CKD. Since the effectiveness of this approach has not been fully studied, a trial has been suggested (137) and such a trial is currently in the advanced planning stages in Canada.

5. Organizing care for people with CKD.

Care for CKD involves seeking a reversible etiology, removal or control of factors promoting progression, assessment and treatment of metabolic complications of kidney failure, and documenting and controlling associated cardiovascular disease (17,141,142). This requires considerable resources and integration of care between patients and multiple healthcare providers including primary care and specialist physicians, specially trained nurses, dietitians, social workers, and pharmacists (143). Fragmentation of care and financial barriers are issues (144). Recognizing these issues, patients with advanced CKD are increasingly cared for in hospital-based multidisciplinary clinics. These clinics, staffed by specialized nurses and nephrologists, with more variable involvement of other health care professionals, have sometimes been associated with improved outcomes (145,146). One trial that failed to show a benefit left it to primary care providers to implement suggested interventions (147). Although discussed, such a care pattern has not been widely used for people with less advanced CKD (148). However, considerations of care complexity and cost, need for specialized knowledge, and concentration of necessary resources, underlie a trend to disease management for people with a variety of serious chronic diseases. Indeed the gaps in care cited above in relation to CKD have also been documented in relation to a host of other treatable chronic diseases and conditions including hypertension, diabetes, tobacco addiction, hyperlipidemia, congestive heart failure, asthma, and depression.

As discussed by Bodenheimer and colleagues, the urgent symptoms and concerns of patients often crowd out the less urgent need to optimally control chronic conditions (148a). However, this "tyranny of the urgent" often substitutes transitory and non-life threatening concerns for ones that will have immense consequences for the patient, their family and society if not adequately dealt with. In an effort to focus thinking on how best to address these gaps, a chronic (disease) care model has been proposed (148a). This model recognizes the role of the community, public and private policy, the health care system and it's financial incentives, along with health care providers and how they are organized and functioning to deal with chronic disease issues. The model further identifies 6 essential elements: community resources and policies; health care organizations; self-management support; delivery system design; decision support and clinical information systems. This model is seen as operating at the primary care level in particular. This is quite appropriate for CKD as well, as the number of individuals affected and the multi-system nature of the associated problems require a generalist and longitudinal focus. Such a model would require considerable reorganization of current systems to emphasize: 1) greater linkage to community resources; 2) reorganization of health system financing to reward high quality chronic disease care; 3) an emphasis on maximizing and resourcing self-management by those affected (e.g. promoting rather than under paying for glucose monitoring etc); 4) creation of practice teams within which physicians focus on acute care, difficult chronic cases and training of other team members. The other team members in turn would need to support and problem solve around self-management issues, and arrange and perform periodic checks; 5) greater incorporation of decision support aids by reminders and incorporation of evidence based guidelines; 6) all supported by enhanced electronic clinical information systems capable of providing reminders, feedback on performance and outcomes and serving as a basis for planning services to individuals and populations.

Care in specialized clinics, but not efforts to co-ordinate primary care by telephone, reduced hospitalizations and costs for those with heart failure (149). Processes of care, hospitalization, quality of life and functional status were also generally improved by similar approaches to those with coronary heart disease (150). Disease management has been defined as "a multidisciplinary, continuum-based approach to healthcare delivery that proactively identifies a population with, or at risk for, medical conditions that 1) supports the physician/patient relationship and plan of care; 2) emphasizes prevention of exacerbation and complications utilizing cost-effective, evidence-based practice guidelines and patient-empowerment strategies, and 3) continuously evaluates clinical, humanistic and economic outcomes with the goal of improving overall health" (151). Integrated information management, including primary data collection from wherever patients receive care, and ongoing analysis aimed at improving the quality and efficiency of care, is another key requirement for optimal application of multiple interventions in a disease management model (148,156). Reports of positive impacts of this approach to chronic disease care emerged as early as 1975 (152). A recent systematic overview found positive effects of disease management on care processes and intermediate outcomes, such as glycemic control in type 2 diabetics (153). Similar conclusions were reached by reviewers focusing on studies of the impact of elements of the chronic (disease) care model in diabetes care (153a). Although many trials have found reduced hospitalization and costs (153a,154), other existing economic analyses are limited by reliance on administrative data and incomplete accounting of program costs (155). The overview emphasizes the need for further studies of disease management on longer-term clinical and economic outcomes in diabetics (153). Disease-management has also been applied to dialysis patients, with apparent improvement in hospitalization and mortality (156). However, people chose to opt-in to the disease management program, there was limited adjustment possible for case-mix, and reliance on administrative data precluded comprehensive comparison of outcomes (156). Disease management programs have been acceptable to primary care physicians, especially when they have remained an integral part of the care team (157). Patient identification, reminders to use efficacious interventions, and process design facilitating concentration of resources may be more critical than which professional provides the care (158,159).

Nurses, collaborating with physicians already effectively deliver protocol based care in nephrology (160). Nurses as care managers in disease management programs have been seen to have an important role in care for people with CKD (156,161,162). Nurse practitioners, with higher education in nursing, are well suited to care for people with CKD. These nurses maintain and restore health; emphasize wellness and self-care; complete medical histories and physical exams; diagnose and treat acute health problems; monitor and treat chronic diseases; and prescribe medications and other treatments. In the U.S., nurse practitioner care has been "as good as or better than care provided by physicians" and they have been found to have "better communication, counseling, and interviewing skills" (163).

6. Intensified care for CKD may be economically attractive.

Dialysis and hospitalization for cardiac and kidney disease are very costly. Recent analyses suggest that even a 10% reduction in the rate of progression of CKD could lead to significant savings in ESKD treatment costs, which if targeted well, could be used to fund secondary preventive care (140). The cost-effectiveness of many of the individual interventions outlined above has previously been examined. A recent analysis showed that more intensive blood pressure reduction in type 2 diabetics both reduced costs and increased quality-adjusted life expectancy (164). In the same study the cost-effectiveness of statin-based lipid lowering was not as attractive, but the result was strongly influenced by the assumption that patients would survive longer and develop the costly kidney complications. This result in turn was due to the assumption that blood pressure would not be intensively controlled in the same patients (164). However, determination of the cost-effectiveness of multiple risk factor intervention will require further study in a prospective concurrent clinical and economic trial. If for argument sake such a trial showed that 5 years of dialysis could be avoided for each 400 patient-years in clinic, the direct dialysis health care costs avoided by this alone would be in the range $130,000 to $274,645. Other potential economic gains would include reduced costs for management of advanced cardiac disease, and increased productivity to society by delaying disease advancement and having less ill patients. These direct and indirect cost savings could more than offset the cost of providing targeted enhanced care to those with CKD. Further research is planned to examine the cost-effectiveness of at least one new approach patterned on aspects of the chronic (disease) care model.

7. Issues in implementing a change in care patterns for CKD.

The evidence base has some gaps. There remains a lack of certainty from rigorous clinical studies that some of the specific therapies, known to benefit those at risk for cardiovascular disease events, will confer similar benefits in those with CKD. In addition, the cost-benefit of broadly applied intensive treatment approaches is not yet clear as some of the projected savings relate to avoidance of ESKD, a goal that has not yet been demonstrated feasible in large populations. A move to substantially alter current primary and specialized care systems to manage chronic illness requires organizational leadership that may be lacking if no one organization sees this task as its role. In the ESKD setting in the United States, this and some other barriers have been overcome by contracting out responsibility for the care organization. However, such a solution might not fit well with the Canadian model for financing and providing health care services. Identification of patients appropriate for this care pattern may be challenging, but could be based on laboratory test results, claims data and electronic patient visit records. Patients with CKD often move between health care providers, thus not only fragmenting attempts to organize longitudinal care management, but also affecting the economic incentives for the practitioners and organizations involved. Novel healthcare financing arrangements will be required, as current systems often fail to provide incentives and may provide disincentives to a proactive approach to chronic disease care. The protocols and guidelines supporting therapy need to be evidence based and continuously updated, a task that many individuals and smaller organizations may lack the capacity to perform. A central source for such protocols, on at least a national basis, requiring local adaptation will probably be of benefit. In addition, providers practicing in the traditional mode will need to switch to a proactive, organized approach involving patient scheduling (including reminders), delineation of roles for a variety of practitioners, team organization, and information management. The technical and human resources need to provide and operate the information technology necessary to the optimal functioning of this model will require considerable up-front resources. However, the move towards the electronic health record would support this change.

8. Care for advanced CKD prior to ESKD.

Advanced renal failure requires complex care. Preparation for dialysis and transplantation takes time and late referral to nephrology services has been associated with greater morbidity, mortality and higher costs (126-135). The variety of skills and resources required to provide this care has led to development of specialized multidisciplinary teams to work in concert with primary care providers. This team should include a nephrologist, a specially trained nurse, a dietician, and a social worker. Clinical pharmacy, psychology, psychiatry, physiotherapy and occupational therapy services, if available, add other important professional skills to the team. Different models can be used. One model, described by Levin et al (145) demonstrated better patient outcomes at the initiation of dialysis in a cohort of CKD patients followed in a multidisciplinary clinic compared to those followed in nephrologist offices.

Patients with advanced CKD should be managed using strategies to slow the rate of progression of kidney disease and to deal with the complications of uremia, including treatment of anemia, cardiovascular disease, bone disease and nutrition. Decisions regarding choice of ESKD treatment modality require patient and family education. Timely referral provides sufficient time to prepare patients for the selected modality and to permit timely initiation of dialysis or transplantation. Canadian national recommendations emphasize timely referral to maximize potential gains from involvement of specialized nephrology teams (141). The recommendation that referral occur at a creatinine clearance of 30 ml/min is to allow sufficient time to prevent or treat complications of uremia and to prepare for ESKD treatment, either by dialysis or transplantation.

At present multidisciplinary teams to care for those with advanced CKD are in place in St. John's and Corner Brook. A nephrologist is working on-site in Grand Falls and a nephrologist visits most of the larger population centres in the province on a regular basis to provide ambulatory and consultative care to patients with CKD. Patients seen at sites other than St. John's, Corner Brook and to some extent Grand Falls, do not currently have access to the skills of a multidisciplinary team for advanced CKD care. Referral of such patients to the sites in St. John's and Corner Brook for education does occur, but the intensity and continuity of involvement with the required range of specialized services is often sub-optimal in these cases. This has implications for choice of ESKD treatment modality and likely increases the costs of care.

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Module C

Peritoneal Dialysis

Description of the Technique

Peritoneal dialysis (PD) is a form of dialysis treatment for endstage kidney disease. Patients using PD have plastic catheters placed through the abdominal wall into the peritoneal cavity or space around the bowels. These catheters, or tubes, have several openings on the end inside the patient while there is a single opening at the other end of the tube which is outside the patient. The outside opening is connected to a disposable or exchangeable piece of tubing called a transfer set, which is exchanged approximately every six months. A capping locking device closes the end of the transfer set preventing access to the peritoneum when not needed. With current peritoneal dialysis techniques the patients connect their catheters to sources of dialysis fluid intermittently. Several variations on PD exist. The most commonly employed is known as Continuous Access Peritoneal Dialysis (CAPD). With CAPD, bags of specially prepared fluid are connected to the peritoneal catheter anywhere from four to six times per day. Using a gravity pressure system, the fluid is allowed to flow into the abdominal cavity where it is retained between bag changes. At the end of a specific dwell time the fluid is allowed to flow out by gravity into another empty bag attached to the catheter. The most commonly employed bag systems at present are known as Twin Bags and have both an empty and a full bag connected via a Y shape tube to the patient's abdominal catheter. When exchanging abdominal fluid, patients have to collect the necessary supplies, wash their hands thoroughly, ensure sterility of the catheter cap, connect the tubing from the bags to the catheter, empty their abdomen of fluid, and fill with fresh dialysis fluid. This whole procedure typically takes about half an hour at a time. Since patients generally do this around four times a day, the time required is approximately two hours daily. Peritoneal dialysis is done every day of the week. A variation on CAPD uses a relatively simple machine called a Cycler to automatically perform fluid exchanges while the patient is asleep at night. The Cycler is programmed to exchange the required volume of fluid at a pre-arranged time. Patients using the Cycler have less of a need to exchange fluid during the day and typically exchange their fluid once or twice apart from when they connect and disconnect from the Cycler.

Peritoneal dialysis is a home-based therapy. Systems exist to deliver the necessary disposable supplies to patients' residences. The technique, although technically complex, is not as complex as haemodialysis. Training programs can train patients themselves, or members of their families can usually learn to carry out this technique safely after approximately five days training. The training is provided by specifically experienced nurses.

Indications, Contraindications and Outcome of Peritoneal Dialysis

Peritoneal dialysis is an option for virtually all patients requiring dialysis for endstage kidney disease. There are a few medical contraindications to peritoneal dialysis. These include abdomens with lots of prior surgery and scars, which would make it difficult to insert a catheter. In addition, large existing hernias that cannot be satisfactorily repaired would preclude peritoneal dialysis because of the risk of complications from the hernias or leakage of peritoneal fluid. Patients with advanced lung disease or severe back problems may have their breathing or back pain worsened by the existence of fluid in their abdomen and would also be relatively contraindicated for peritoneal dialysis. Other relative contraindications include those related to hygiene. Development of infection in the abdomen is a complication of peritoneal dialysis and would be worsened by poor patient hygiene. Poor patient eyesight and manual dexterity are also inhibitors to patients carrying out their own peritoneal dialysis exchanges. Oftentimes patients have family members, friends or neighbours who are able to assist them with the technique. In other cases it has been necessary to train and pay home support workers to assist patients with their peritoneal dialysis.

Patient preference has been a major factor in determining which modality of dialysis is provided. Several studies have looked at this issue in the past. Work done in Quebec during the last ten years suggests that when patients are fully informed about the advantages and disadvantages of each form of dialysis, that approximately 50% might choose peritoneal dialysis and 50% haemodialysis methods.(1) Historically in Newfoundland, geography has been a major factor influencing choice of modality. Where haemodialysis facilities were not available and the home-based peritoneal therapy was, a large proportion of patients undertook peritoneal dialysis.

Medical outcomes of peritoneal and haemodialysis are fairly similar.(2,3,4) Several studies have compared mortality in the first number of years after initiating dialysis for end stage kidney disease. In general, the trend seems to be to equivalent survival. The studies have been hard to interpret in part because of a lack of comparability of patients starting PD versus haemodialysis. Adjustments have needed to be made for severity of illness and a variety of other factors that might influence outcome. Certainly Canadian data analyzed recently by Newfoundland nephrologists would suggest that survival is equivalent for the two techniques.(2) Quality of life has not been formally compared as often and would be plagued by the same biases that make it difficult to compare survival across dialysis modalities. Hospitalization has been compared across techniques and again requires adjustment for case mix. There may be slightly more hospitalization associated with the use of peritoneal as opposed to haemodialysis, but any difference is modest.(5)

System Requirements for Peritoneal Dialysis

To successfully operate a peritoneal dialysis program requires several things to be in place. Specific training resources are required to assist patients in making modality selections. These are best based at interdisciplinary Nephrology clinics where patients and their families can be educated regarding all aspects of kidney disease and its treatment, including dialysis and transplantation. Since such education can take time, it is critical to foster systems whereby patients are seen in such clinics many months prior to needing dialysis.

Once a decision has been made to pursue peritoneal dialysis, surgical services are required to place the peritoneal catheter. Traditionally in Newfoundland, this has been done by open surgical technique in the operating room. National and international trends, however, support the use of minimally invasive surgical techniques when placing peritoneal catheters. Such techniques require specific operator skill, but minimize the exposure to anesthetics and permit outpatient placement of catheters, likely reducing costs. This surgical technique is available through at least one practitioner in St. John's. In some provinces nephrologists have this expertise, but nephrologists in

Newfoundland are not trained in this procedure. Other surgeons who insert peritoneal catheters in patients have not utilized minimally invasive techniques.

Once catheters have been placed, an initial brief training is required instructing the patients and/or their caregivers in dressing the exit site and periodically injecting saline with heparin into the catheter. The training has traditionally been carried out by the peritoneal dialysis nurses. Usually several weeks later, the patient and/or family return for complete training in peritoneal dialysis. This is carried out by specifically trained nurses. Currently, this training is centralized at the Waterford Hospital site; however, since February 2003 patients from the Western Region are managed at Western Memorial Regional Hospital. Training is now generally carried out on an ambulatory basis. As the training takes approximately five to seven days to complete, patients and/or their families must stay in the area during this time. In St. John's this has been generally at the hostel associated with the Health Care Corporation.

Patients return home following completion of training. A system operated by supply vendors is in place to deliver supplies when patients need them. Problems associated with the supplies may be communicated directly to the vendors. Nevertheless, it is important for the peritoneal dialysis nursing staff to be able to respond to problems that arise. For these, and other medical care issues, a follow up by telephone outreach is generally offered for all patients on home-based dialysis therapy. This requires specifically trained nurses to be available during working hours at least. Patients know how to contact these nurses for many types of questions that arise in relation to their dialysis or overall health needs. There is an absolute requirement for such nursing resource. Nephrologists do not consistently have the time available, or sometimes the technical familiarity with the equipment, to deal with the types of questions and concerns that patients raise. Family doctors and other community physicians are not sufficiently knowledgeable of peritoneal dialysis to address these issues either. The current system involving co-ordinated medical and nursing care through the Nephrology centers in the province works well. This system is currently based in St. John's and Corner Brook. Although individual or small numbers of nurses at other sites across the province have been trained in peritoneal bag exchange, these nurses have not been trained in follow up of patients or the teaching of new patients. It would be difficult for full training to occur at various sites due to nursing staffing turnover and inefficiencies due to small patient numbers. In general, one specially trained nurse should be capable of following 30 to 60 patients. The intensity of follow up varies depending on the illness severity and abilities on the part of individual patients and their families to perform the dialysis. If the peritoneal dialysis nurses are also involved in training either health care staff or patients and families, then their ability to undertake follow up is impacted. A nurse who is also responsible for training would only be able to follow 30 to 40 patients.

As patients on peritoneal dialysis are largely treating themselves at home, there is a need for periodic review by medical and nursing staff. The geographic dispersion prevents that being done in patients' homes. Nephrologists have undertaken outreach clinics in all major centers for many years. The frequency of outreach clinics varies from once a year in Happy Valley-Goose Bay and Labrador City to twice a year in St. Anthony and Burin, five times a year in Clarenville, six times a year in Grand

Falls-Windsor and Carbonear and monthly in Gander. A nephrologist is currently on site in Grand Falls-Windsor, but has had no involvement with the peritoneal dialysis program. A nephrologist currently working in Corner Brook is responsible for medical follow up of patients on peritoneal dialysis from the Western Region. In the outreach clinics, the nephrologists undertake medical follow-up and review of patients on peritoneal dialysis. The nurses supply data gathered in the interval since the last medical clinic review, including laboratory data and measures of dialysis adequacy, for review with the patient by the physician. Other patients take advantage of the opportunity to be reviewed in the Nephrology clinics in St. John's and Corner Brook. At these clinics a more immediately co-ordinated and integrated nursing and medical review can occur. All peritoneal dialysis patients are seen approximately every three months, and more often depending on health needs.

The following is a quote from a young woman with personal experience of peritoneal dialysis, haemodialysis and renal transplantation.

> *"In 1989 my daughter was born and shortly after I went into renal failure. Three weeks later I started haemodialysis which was a very difficult time for me both physically and mentally. Although I was only on haemodialysis for approximately one month I quickly realized how uncomfortable it was. Before I began my dialysis I would be very tired due to the build up of toxins in my blood. While I was on the machine I would feel sick, the machine not only removed toxins but also salt which would cause extreme cramping in my legs. Just the ordeal of getting my blood cleansed would tire me out and it would take until the next day to feel better. I received haemodialysis three times a week, 3-4 hours each time at the renal unit. It was not only physically draining but also mentally. Also it was very stressful being away from my family, especially my daughter. I was just too tired to take care of her when I got home from dialysis.*
>
> *After being on haemodialysis for a month I was approached by my doctor at the renal unit about peritoneal dialysis. I was scared at first but as time went by I became more familiar and comfortable with the procedure and it got much easier. I would drain dialyzing solution into my peritoneal cavity and 6 hours later would drain the solution out with the aid of a machine. Even though I did this procedure more frequently (4 times a day, every day), I felt much better both physically and mentally. My blood was being cleansed continuously and there was no build up of toxins in my body. Personally I felt like I had my life back again and I was in control. I could take care of my children and do my dialysis in the comfort of my own home and not in the hospital. I could go camping and do the "so called normal " things a family would enjoy doing. It is very important to have a support system in place while on peritoneal dialysis whether it is family, friends, or medical staff. Fortunately I had all three, especially family.*
>
> *In conclusion, I would like to say, I had a good experience while on peritoneal dialysis. I did this for 20 months. Then on March 27, 1991, I received the greatest gift of all, a kidney from my brother. It has been almost twelve years now and I am doing great."*

There has been a decline in the proportion of dialysis patients using peritoneal dialysis over the past five years in Canada generally and particularly in Newfoundland. Historically, as mentioned above, geography was a factor influencing choice of modality in this province. At one time approximately 40% of dialysis was of peritoneal type in Newfoundland. Currently, there are 66 patients on peritoneal dialysis as opposed to 259 patients on haemodialysis. This distribution is broadly similar to that in Canada.

Several potential explanations for the decline in the proportion of patients on peritoneal dialysis have been offered in the past. Older comparisons of survival on the two techniques did not adequately account for case mix and suggested that patients on haemodialysis might do better. This may have influenced some practitioners and patients in their choice of modality. A large observational cohort study called the CANUSA study was published a number of years ago. This study has been influential in shaping the practice of peritoneal dialysis across Canada and the United States. The study suggested that peritoneal dialysis might not provide the same degree of clearance of kidney failure toxins from patients, once the patient's own native kidney function had declined to a minimal level. This tends to happen within one to two years of starting peritoneal dialysis. Some people erroneously interpreted the study as suggesting that patients could not be maintained on peritoneal dialysis beyond a period of two to three years. The study design utilized a fixed standard prescription of peritoneal dialysis similar to that prevalent at the time the study started. More recent practice would adjust the intensity of peritoneal dialysis to achieve so-called adequacy targets by increasing the volume of fluids passing through the peritoneum. While it is clear that this cannot completely replace existing native kidney function, it is also true to say that many patients can be maintained on peritoneal dialysis quite well for relatively long periods of time as long as attention is paid to ensure that they remain in good health. A further factor that likely changed the utilization of peritoneal dialysis was the increasing availability of haemodialysis facilities in smaller communities. Historically, the more technically demanding haemodialysis has been offered in large urban centers, often associated with university hospitals. With the increasing technical sophistication of the dialysis machines, and the lower dialysis associated complication rates, haemodialysis has increasingly been offered in smaller communities over the past decade. This has reduced some of the geographic barriers to accessing haemodialysis. Accordingly, peritoneal and haemodialysis are now both being offered as options to patients residing in most parts of the country. The haemodialysis is often delivered in-center by trained staff. As such, patients require lesser training in order to take advantage of this modality of treatment. Without appropriate resources to educate patients about the advantages and disadvantages of each dialysis modality, it will likely be the case that patients will drift towards the form of treatment that requires less direct involvement by themselves. While haemodialysis facilities have diffused into smaller communities, the required resources to prepare and educate patients for choice of modality has not necessarily followed suit.

Issues With the Current Delivery of Peritoneal Dialysis Services in Newfoundland and Labrador

1. Centralizing provincial service delivery at only two sites (St. John's and Corner Brook) is efficient, but does pose a challenge for patients who live at a considerable distance with regard to frequency of in-person review.

2. There has been a major decline in the proportion of patients receiving peritoneal versus haemodialysis over the years. Factors associated with this have been discussed above. The result of this trend has been an increase in the average cost of dialysis provision within the province.

3. Patient preparation and education with regard to modality selection is currently sub-optimal in that it is unevenly applied across the province. Patients require considerable time and education in order to understand the complexities of end stage kidney disease and its treatment. While special clinics to facilitate this education have been set up in St. John's and Corner Brook, these interdisciplinary clinics do not exist in a well-developed form in any other part of the province. As patients with chronic kidney disease, who are not yet on dialysis, are often reluctant or unable to attend the clinics in St. John's and Corner Brook on a regular basis, they can suffer from a lack of education and orientation with regard to dialysis modality choice. The impact of this has been to a greater tendency to place patients on haemodialysis, which requires much less patient education. Greater effort is required to orientate patients to the nature of the tasks involved and the advantages and disadvantages of home-based therapy, such as peritoneal dialysis. This is not optimally offered through the current outreach Nephrology clinics. The physicians staffing these clinics are extremely busy on the days that they are seeing patients and do not have the time or, indeed, the skills to undertake all the education required.

4. There has been variable access to surgical services for placement of peritoneal catheters. Peritoneal catheters have been exclusively inserted by surgeons working in St. John's up to the present time. This poses a challenge for patients starting the technique, as they are required to travel to St. John's for this service. As placement of peritoneal catheters is not technically complex, it should be within the realm of most general surgeons. The minimally invasive techniques for placement of catheters are preferred, but require more specific training and skill. There is a need to develop greater access to surgical services for placement of peritoneal catheters, including minimally invasive techniques across the province.

5. There are advantages to purchasing supplies and equipment in bulk. With the historical base of the Peritoneal Dialysis Program in St. John's came the advantage of centrally negotiating contracts with suppliers for larger quantities of supplies at lower costs. The recent division of responsibility for peritoneal dialysis services between St. John's and Corner Brook, makes it important to consider how to maintain a provincial tendering system for peritoneal dialysis related supplies and equipment.

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Module D

Haemodialysis: A Comparison of Service Models

Haemodialysis Therapy

Dialysis can be delivered through blood based methods called haemodialysis which uses a machine or through peritoneal dialysis which involves a catheter placement in the abdomen. For haemodialysis, the patient has to have access to their circulation created, and they are then generally required to attend a dialysis unit for 4 to 6 hours at a time, three days a week to receive therapy. This type of dialysis can be done in the home, but is relatively technically complex and demands a degree of skill, ability, and availability of a helper, such as a spouse, parent, or other. Currently, this renders home haemodialysis unavailable for many elderly, who may not have such a helper available on a regular basis. At present, there are 3 patients in the Province on home haemodialysis. Haemodialysis in a dialysis unit is carried out by specially trained nurses. Each patient is seen in the unit by a nephrologist on a regular basis. At present, in this Province, dialysis units are located in St. John's, Clarenville, Grand Falls-Windsor, Corner Brook and Stephenville.

Haemodialysis Services in the Province

In Newfoundland and Labrador, haemodialysis has been available in St. John's for many years. In 1974, a dialysis unit was opened at Western Memorial Hospital and the population served there has grown over the years. This unit functions quite independently with two nephrologists on staff as well as an intervention radiologist and a surgeon who does the vascular access. In early 1998, a unit was opened in Grand Falls providing haemodialysis service for much of the central part of the Province. Care at this unit is provided by internists with detailed backup provided by nephrology services in St. John's as there is no nephrologist on staff.

These haemodialysis services are hospital based with no specific limitation on the kind of patient able to access these services. By this, it is meant that the level of acuity and comorbidity of the patients has not dictated whether or not they could be dialyzed in these settings. The renal services in St. John's are considered to be tertiary care and provide backup for the patients both in Corner Brook and to a greater extent in Grand Falls. The back up includes surgical, interventional radiologic and tertiary care Nephrology services.

In July 2001, a 4 station haemodialysis unit was opened in Sir Thomas Roddick Hospital, Stephenville. Even though this is a hospital based unit, it operates as a satellite unit of Western Memorial Hospital, Corner Brook. Nephrology services are provided from Corner Brook and the people receiving treatment are restricted to those who are medically stable. This unit was an initiative of Western Health Care Corporation to decentralize haemodialysis services and relieve some of the pressures from the unit in Corner Brook.

Also in July 2001, a community based haemodialysis unit was opened in Clarenville. This unit is operated as a satellite unit of the Health Care Corporation of St. John's. It is under the administration of Health & Community Services - Eastern Region but the medical direction is provided by the Nephrology Division at the Health Care Corporation of St. John's. Services at this satellite unit is restricted to medically stable patients who are selected by the nephrologist based on established eligibility criteria. As this is the first community based unit in this province, an evaluation has been conducted following its first year of operation.

Requirements for Delivery of Haemodialysis in Different Service Models

Haemodialysis can be delivered through different service models. These include:

1) Hospital based units which have a full medical team of nephrologists, intervention radiologists and surgeons who provide the vascular access for patients. This unit would also have specially trained nursing staff, other health professionals such as dieticians, social workers, pharmacists as well as clerical support. These units are capable of providing services to people whose condition is at a high level of acuity and complexity;

2) Hospital based satellite units which are generally operated under the direction of the larger hospital units described in (1) above. The medical staff supporting this unit would not include a nephrologist, intervention radiologist or surgeon on site. For this reason, there is a limitation in the kind of patient able to access these services. Only medically stable patients attend these units. The care is provided primarily by specially trained nurses. Other professional services such as dietician or social worker are generally not available or on a very limited basis. At present, the unit in Grand Falls-Windsor is operating as a service somewhere between models (1) and (2). Even though there is a nephrologist on site, the medical direction available is deemed to be insufficient. Support from the Nephrology Division at the Health Care Corporation of St. John's is still warranted.;

3) Community based satellite units which operate under the medical direction of a hospital based unit described in (1) above. As it is located outside the confines of a hospital, the only professional staff on site would be nursing staff. The community based unit presently in operation in this province is administered by a Health and Community Services Board and is located in one of their leased office buildings. Only medically stable patients can be accommodated in this type of unit;

4) In the home where a family member or friend usually performs the treatment. Patients have to be medically stable with few problems during dialysis to avail of this type of treatment. Each of these models has different implications for human and other resources as well as the type of patient they can serve.

In considering the establishment of haemodialysis services, the implications for each of these models must be examined. These implications are outlined below:

Implications for Different Haemodialysis Service Models

	1) Full Hospital Unit	**2) Hospital Satellite Unit**	**3) Community Based Satellite Unit**	**4) Home Haemodialysis**
Space & Water Supply	Specially prepared hospital space with water treatment system and water storage tanks. Biomedical Technicians maintain the water supply. All support systems, eg. laboratory, emergency, pharmacy, medical supplies, laundry and housekeeping are readily available within the hospital.	Specially prepared hospital space with water system and other supports similar to #1.	Specially prepared non-hospital space with reverse osmosis water system. No back up tanks are needed with this system. There is no Biomedical Technician on site. Nurses are responsible for maintaining the water treatment system. This unit is located in non-hospital space, generally with direct access to outside. As this unit is in a non-hospital community building, there is no immediate access to support services such as laboratory, pharmacy, laundry or housekeeping. These services must be contracted and the unit must be stocked with necessary supplies in order to be self sufficient.	Specially prepared home space with a portable water system. Being outside the hospital boundaries, all services must be arranged from outside.

	1) Full Hospital Unit	**2) Hospital Satellite Unit**	**3) Community Based Satellite Unit**	**4) Home Haemodialysis**
Machines & Supplies	Mixture of types for special circumstances.	Standard delivery systems and supplies. Machines and supplies need to be the same as the main hospital unit which supports the satellite unit for ease of trouble shooting.	Standard delivery systems and supplies. Machines and supplies need to be the same as the main hospital unit for ease of trouble shooting. As support is at a distance, there is a computer link with the in-centre unit.	Patient specific delivery system and supplies. Machines presently used in this Province are the same as those used in the main hospital unit. However, machines, especially designed for use in the home, are currently being manufactured and tested. These should be available in the very near future and will be a less costly model.
Nurses	Specially trained nurses in high ratios. The nurse to patient ratio will be dependent on the acuity of the patients. There may be 1 nurse to 2 patients or as low as 1 nurse to 4 or 5 patients. A minimum of 2 nurses is required in a unit if there is more than 1 patient. In the larger hospital units, greater staffing efficiencies can be achieved because of the higher patient volumes and staff mix possibilities.	Specially trained nurses, may be in lower ratios. As patient conditions are not as complex, the ratio may be 1 nurse for 3,4, 5 patients. There must be two nurses in the unit, however, if there is more than 1 patient.	Specially trained nurses in high or low ratios. With the practice of having a minimum of 2 nurses in unit if more than 1 patient and community based satellite units generally have low numbers of patients, the nurse to patient ratio is higher than in larger hospital based units.	Usually nurses do not provide service as treatments are done by family members or a friend. Nursing staff at in-centre units are available by phone for support and advice.

	1) Full Hospital Unit	**2) Hospital Satellite Unit**	**3) Community Based Satellite Unit**	**4) Home Haemodialysis**
Physicians	Nephrologists as well as an intervention radiologists and a surgeon are required in tertiary units. Nephrologist or experienced internists with nephrologist back up are needed in non-tertiary unit. An intervention radiologist and surgeon must be accessible when needed.	Nephrologist from larger hospital unit provides follow-up and direction regarding medical services. Experienced Internists on staff at the satellite site may provide some medical services under the direction of the Nephrologist depending on the medical stability of the patients in the unit. Intervention radiologists and surgeons are accessed at a larger hospital centre when necessary.	Nephrologist provides care at a distance and periodically visits and reviews patients. Referral to an intervention radiologist or surgeon is made when necessary.	Nephrologist provides care at a distance and periodically reviews patients. Referral to other medical personnel as required.
Other Staff	Full complement of biomedical technicians, licensed practical nurses, dietician, pharmacist, social worker, management and clerical staff.	Biomedical technician usually shared with another unit. No licensed practical nurses. Less than full-time dietetic, social worker, pharmacy support. Limited management and clerical support on site.	Biomedical technician backup from main unit. No licensed practical nurses. Dietetic, social worker or pharmacy support not available on site. Limited management and clerical support on site.	Biomedical technical backup from main unit. Usually a trained non-professional to provide dialysis.
Patient Characteristics	All levels of acuity and complexity in tertiary and most levels in non-tertiary units.	Medically stable patients with few problems during dialysis. If condition of patient changes, referral is made to major hospital unit.	Medically stable patients with few problems during dialysis. If condition of patient changes, referral is made to main hospital centre.	Medically stable patients with few problems during dialysis. Patients are referred to dialysis units if condition changes or support not available in home.

	1) Full Hospital Unit	**2) Hospital Satellite Unit**	**3) Community Based Satellite Unit**	**4) Home Haemodialysis**
Response to emergencies	Immediate and complete on the premises. Exceptional circumstances may require transfer to tertiary centre.	Varies depending on location and level of hospital and medical support in hospital.	Backup by phone, then transfer by ambulance.	Back up by phone, then transfer by ambulance.
Electrical Outage	Hospital Emergency electrical backup available.	Hospital Emergency electrical back up available.	No emergency electrical back up available.	No emergency electrical back up.

Challenges for Haemodialysis Service Models

Full Hospital Model

Full hospital based model requires specialized staff and back-up services including a nephrologist to meet the needs of people whose medical conditions are not stable. It is more efficient and cost effective to put these services in areas where there are sufficient specialized resources and a higher number of people requiring haemodialysis.

The development of space, including a water treatment system can be quite costly especially if it is redevelopment of existing space . It should be noted that development of new space for the satellite unit in Clarenville cost far more than originally anticipated. A space utilization study conducted in 2001 for Grenfell Regional Health Services also estimated renovation costs in existing hospital space for a 3 to 4 station dialysis unit to be significantly higher than the new space constructed in Clarenville.

The standards for Independent Haemodialysis Facilities, developed and used by the College and Physicians of Ontario since 1994, call for the Medical Director of such a unit to be a subspecialist in the field of Nephrology. These specialists are currently located in St. John's and Corner Brook. Recruitment and retention of a nephrologist would be a significant challenge as the patient volume for dialysis services in some areas of the Province would not support the full time service of a nephrologist. The role of Quality Advisor as outlined in the Ontario standards could then be filled by a nephrologist from outside the area. Nephrologists from the Nephrology Division at Health Care Corporation of St. John's have indicated they are receptive to providing medical support.

Nursing staff for the unit need to be trained and certified as suitably qualified. This training usually can take up from six to ten weeks especially for this model as training in complex cases is essential. Support is then needed from the training centre on an ongoing basis for at least the first year. Staffing needs to be an appropriate ratio to provide care to all levels of patients. The volume of patients need to be at a level that will allow all staff to maintain their skills. This can be a challenge in small units especially for temporary or part-time staff who are needed for leave replacement.

Biomedical technical support needs to be available, particularly after the first year of operation as the haemodialysis machines age. For a full hospital model, other support services, i.e. dietician, social work, laboratory, are a part of the staffing complement.

Hospital Satellite Model

In the Satellite Hospital Unit, the patients would need to be medically stable; their condition would not be of the complex nature that would need immediate services of a nephrologist. All patients would be assessed by a nephrologist and deemed to be appropriate based on established criteria. The criteria established for the satellite unit in Clarenville included the following:

- absence of frequent severe symptomatic hypotensive episodes
- absence of the need for supplementary oxygen
- absence of uncontrolled or unstable angina
- absence of frequent episodes of uncontrolled pulmonary edema.

Hospital based units engender an expectation that very ill patients can receive treatments and be cared for. This is not true if physicians with training in Internal Medicine and experience in haemodialysis are not consistently available. Responsibility for medical follow-up of patients in a satellite unit remains with the nephrologists in the main hospital centre. Some support may be provided by the Medical Internists on site in consultation with the Nephrologist. The challenge would be to maintain this type of unit as a satellite unit providing service for only medically stable patients.

Most hospital satellite units in the Province would therefore have to function as a satellite of the Health Care Corporation of St. John's with the exception of those within the catchment area of Corner Brook. Decisions about capital equipment, dialysis specific disposables, technical back up, staff training, ongoing support for staff and role of the unit Medical Director would rest with the Nephrology Division of the Health Care Corporation of St. John's. This model is consistent with satellite units in other parts of Canada and in general with the standards for Independent Haemodialysis Facilities, utilized by the College of Physicians and Surgeons of Ontario. The development and adherence to strict protocols would be needed to ensure this unit operated under the medical direction of the Nephrology Division at the Health Care Corporation of St. John's. Site visits from the Nephrologists at the Health Care Corporation of St. John's would need to occur on a regular basis. Medical Internists at the site would have to commit to following the direction of the Nephrologist when providing services to haemodialysis patients.

The staffing needs for nursing would be similar to that needed in a full hospital unit. The ratio could be lower as the acuity and complexity of patients in this unit will not be as high. Nursing staff will need to be trained at the Health Care Corporation and for the first few weeks staff from the Health

Care Corporation of St. John's will need to be on site in the satellite unit. Back up support by phone will need to be available from Health Care Corporation of St. John's on an ongoing basis.

As the appropriate backup medical and nursing support is needed to ensure quality care to patients in a satellite unit a strong collaborative relationship between the in-centre hospital unit and the satellite unit is crucial. Having a Memorandum of Understanding in place ensures that the relationship is clearly defined. The evaluation reports from the Stephenville and Clarenville units indicate that there are ongoing difficulties with the existing arrangements. A common thread seems to be the perception of staff in the satellite unit that there is not sufficient medical and nursing support from the in-centre unit. Being a very specialized and technical service, staff need time to build confidence in their skills and ability to practice in such an independent environment. The in-centre units must be prepared to provide intense backup support for at least the first one to two years. In small units where there may be rapid turnover of staff, this may require an ongoing commitment on the part of the in-centre unit. Concern has been expressed from the Health Care Corporation of St. John's regarding the impact of satellite units on the workload of their nursing staff, in particular nursing management.

The machines and supplies will also need to be purchased in collaboration with the Health Care Corporation of St. John's, to facilitate trouble shooting from a distance. Providing support for a satellite unit will require ongoing commitment from the in-centre site and support from their executive team before any plans are initiated.

Community Based Satellite Model

The Community Based Satellite Unit can be as small as one or two machines set up in a non-hospital space. Larger variations are possible depending on the need in the community. This model is limiting in that it can only provide services for very stable patients. Such patients rarely have major symptoms during dialysis, have stable vascular access and not regularly require admission to hospital for care of other illnesses.

Having the satellite unit outside the hospital lessens the likelihood of having pressure to provide care for people who could not safely be cared for because of non-availability of a full range of service. If a satellite unit was located in a hospital, there is a possibility that there would be the perception of the unit as equivalent to a fully staffed hospital based unit.

As there are no Medical Internists on site in a community based unit, medical backup is by distance, primarily as telephone contact. The nephrologist functions as the Medical Director at a distance and is responsible for reviewing patient information on a regular basis. The nephrologists hold regular clinics to assess the status of patients and visits the unit periodically for support for staff. It could be under the administration of a Health and Community Services Board or an Institutional/Integrated Board, but under the medical direction of the Health Care Corporation of St. John's or the Western Board. Similar to the Clarenville model, a signed Memorandum of Understanding would need to be developed to outline the roles and responsibilities of each organization.

When considering the space for a community based unit, it should be kept in mind that major redevelopment of any existing space would be necessary to accommodate the electrical and mechanical work. This has drawbacks with leased space, particularly with Health and Community Services Board leases which are generally renewed every three years.

A community based satellite unit is staffed by trained registered nurses. As the unit is outside the hospital where support would be readily available, a minimum of two nurses is required for patient safety. This means less efficiency in smaller units. The ongoing issues which continue to challenge the unit in Clarenville are centred around staff training, relief and day to day back up. Training has been carried out in St. John's and four nurses have been trained. There have been occasions when relief staff have come from the Health Care Corporation and travel has to be paid for these staff. Also, there is competition with the Health Care Corporation for the pool of relief staff. Being open three days a week does have its challenges in setting a work schedule, ensuring that nurses get their full time hours and also ensuring the relief staff get sufficient work time to maintain their skills. The nursing staff do everything in the unit, from cleaning up spills to maintaining stock inventory, as well as maintain patients through their treatments. The staffing model would be improved through an increase in the amount of clerical support. The supervision of the unit also has its challenges, managers are community based and travel to various sites, therefore their availability can be limited at times. This type of unit requires considerable support from the nurse manager, especially during start up and in any transition of staff. Similar to hospital based satellite units, the medical and nursing support from the main hospital unit must be readily available on an ongoing basis, particularly in a community based satellite unit where the nurses practice in an office building with no clinical support on site. This can mean that a considerable amount of time and effort will be needed from staff at the main hospital unit. As previously mentioned, concern has been expressed from the Health Care Corporation of St. John's regarding the impact of satellite units on the workload of nursing staff, particularly nursing management. If the satellite model is to be implemented in other areas of the Province, a nursing resource person dedicated to support these units may need to be considered.

In a community based unit, biomedical technical services can present problems. Some Boards, particularly Health and Community Services Boards do not have technicians on staff. This may mean establishing an agreement with another Board to purchase service.

The haemodialysis machines and supplies in the community based unit would need to be the same as the in-centre unit to facilitate staff training and trouble shooting via distance. The acquisition of these would have to be coordinated with the Nephrology Division of the Health Care Corporation of St. John's. In most circumstances, machines are purchased through a contract which purchases treatments as well as other supplies. The contract specifies the number of treatments required to purchase the equipment. Smaller dialysis units will not be able to meet those numbers, and ideally the purchase of machines for smaller units should be made through the hospital based centre to allow for the machines to be paid through incremental treatments.

The satellite unit in Clarenville has faced many challenges during the past 10 months of operation. The numbers of patients seen in this unit has been variable. This unit takes a maximum of six patients, patients, three days a week. As there is no medical support on site, these patients must be clinically stable in order to be seen at this satellite unit. The numbers of clinically stable patients has been on the decline and there is no wait list for this unit. As the numbers decrease, the functioning of the unit becomes less cost effective. The unit is not able to compensate for this by taking unstable patients as this would require a local presence of clinical back up. The outcome of the evaluation will assist in determining the feasibility of having this type of model established in other communities.

Home Haemodialysis Model

This model offers maximum flexibility in where dialysis is delivered. People at great distances from a haemodialysis unit would not have to endure the hardship of travelling 3 times weekly or relocating. However, this model has the same limitations regarding patients having to be medically stable. Haemodialysis is relatively technically complex and demands a degree of skill, ability, and availability of a committed person to assist. A trained person is needed to dialyze each individual in his/her own home and to set up and maintain a dialysis machine in each home.

Home haemodialysis in fact, constituted a significant fraction of the haemodialysis population at one time. The patients however, were not as elderly as they tend to be now. The proportion of haemodialysis delivered in the home setting has fallen substantially over the years across Canada. In 1999, 1415 patients were trained in Canada for home peritoneal dialysis; only 56 were trained for home haemodialysis. Several factors may have contributed to the decline of home haemodialysis: growth of available hospital based units; increasing complexity of haemodialysis equipment; increasingly sick and incapacitated recipients and financial incentives for physicians to provide in-centre dialysis. However, it may again be time to review the desirability of home haemodialysis. The technique has become much safer in that better delivery systems, dialyzers, dialysate, a degree of automation and better alarm and control systems have all led to a decline in the frequency and severity of complications during dialysis. The complexity of the equipment can be reduced by choice of relatively simpler prescriptions. The latter may necessitate longer time undergoing dialysis, but this might not be a problem if the time in transit to and from a central unit were taken into account.

There are, however, various issues that need to be addressed in providing home haemodialysis. These include: workload involved, the need to train home support staff, the issue of cost for training, requirement for several workers to be trained and interactions with medical back up at a distance. The in depth training and technical difficulty would make it feasible for only a few people to be available in an area to provide home haemodialysis. With the intermittent nature of the therapy, one trained person would be able to dialyse several patients if they were in close proximity. This method of treatment might be feasible in a populated urban area but would be difficult to implement in a cost efficient manner in rural areas.

Determining Feasibility of a Haemodialysis Satellite Unit

When determining the feasibility of a satellite unit, either hospital or community based, various factors need to be considered. These factors include:

- the number of people requiring service;
- distance to existing service;
- the availability of specially trained staff, including medical, nursing and support staff;
- availability/capacity of in-centre units for back-up support;
- availability of appropriate space, equipment and supplies;
- establishment of a unit in relation to the provincial plan for renal services; and
- cost implications.

Community based satellite haemodialysis units experience major challenges related to the service being located outside the hospital with the staff practising in a very independent environment.

In both models of satellite units, there are common issues related to supports available to the nurses, staffing issues, site development costs and operational costs. Experience with the satellite units in the Province indicate that this model is a costly service for a small number of people. The difficulties that have been encountered with the satellite models, particularly in Clarenville, have implications for establishing a similar service in other areas.

Module E

Kidney Transplantation

KIDNEY TRANSPLANTATION

Description of the Transplant Process

Kidney transplantation is considered to be the treatment of choice for people with advanced kidney failure (a state known as end-stage kidney disease ESKD). In general, transplantation increases quality of life and costs are less than when people are maintained on dialysis. There are also data indicating a potential survival advantage associated with kidney transplantation.

At present, transplantation is not an option for all patients with ESKD. Many patients with ESKD, being very elderly and sick, are considered medically unsuitable for transplantation. There is also a disparity between the larger number of people who would benefit from a kidney transplant and the more limited number of kidneys available for transplantation. Kidneys for transplantation may be obtained from someone who has died, usually as a result of some brain injuring process (known as a cadaveric donor). In addition, living people can choose to donate one of their kidneys to a person with ESKD, who may or may not be a blood relative. Up to 50% of the people transplanted in some years have received their kidneys from living donors, because of the shortage of cadaveric organs and the somewhat better survival of the transplanted kidneys from living donors. Organ donation programs are evolving and attempting to maximize the retrieval of organs when people die in circumstances where their organs, including kidneys, can be used for transplantation.

Patients with, or approaching, ESKD need to be seen and assessed by a nephrologist and other health care professionals specializing in kidney disease care. Once it is clear that dialysis or transplantation will be necessary, the patients and their families need to be educated about the various options for therapy, including transplantation. In this province this can be done via the multi-disciplinary pre-dialysis clinics operated by the Health Care Corporation of St. John's and Western Health Care Corporation. Patients from other regions may be seen by one of the nephrologists based in St. John's during visiting clinics held at each of the major centers throughout the province on a regular basis. These patients often have to travel to St. John's or Corner Brook for comprehensive education and assessment or testing for transplantation.

Potential recipients and living donors undergo a complete medical history and physical examination. Protocol guided tests are also carried out especially to determine the presence and extent of any existing cardiovascular disease, malignancy or infection. Potential donors are evaluated carefully to ensure that they will not suffer as a result of losing one kidney. Some of the required testing is specialized (e.g. magnetic resonance angiography of the renal arteries in potential donors) and only available at restricted sites throughout the province. Once a person is considered suitable for transplantation, a chart with their assessment results is sent to the transplant center. The QE II in Halifax is currently the regional site for Atlantic Canada, but some cases are referred to other sites if, for example, their living donor lives outside the region. At the referral site, members of the transplant team review the assessment data. The team may agree or disagree with the request to transplant. In some cases further assessments are requested before acceptance. For patients with living donors, the transplant operation is then scheduled and arrangements to have both donor and recipient travel to the transplant center are co-ordinated by specialized staff in St. John's or Corner Brook. In cases where there is no living donor, the potential recipient is placed on a wait list at the transplant center. Patients on the wait list undergo periodic re-evaluation to ensure that they remain suitable for transplantation.

Some patients with Type I diabetes may benefit from transplantation of a pancreas. This tends to be done in conjunction with a kidney transplant, but pancreas grafts (or islet cell transplants) have also been placed in patients not yet in need of a kidney transplant. Up to a couple of years ago a program was offered in Halifax for simultaneous pancreas/kidney transplantation in suitable cases. Success rates were quite good. Unfortunately, following a change in medical staff at the transplant program in Halifax, the pancreas and liver transplant programs there were discontinued. Following prolonged negotiation, an arrangement was subsequently made to have potential pancreas transplant candidates from this province handled via the Toronto program. Logistics proved difficult and more recently this arrangement has been altered to have such patients from this province managed via the program at the Royal Victoria Hospital in Montreal.

Cadaveric kidneys are collected from donors throughout the Atlantic region and generally offered to Atlantic region residents via the Halifax site. Responsibility for co-ordination of organ donation is provincial. The organ procurement program in this province, known as the OPEN program, is based in St. John's, has 1.5 Full Time Equivalent staff, and a regional assistant coordinator position exists in Corner Brook. Staff from the OPEN program provide community education, and liaise with and support staff at hospitals across the province in relation to organ donation. In addition, these coordinators deal with the receiving programs nationally when organs become available. Coordinating the organ retrieval process that may involve teams traveling from sites outside the region, together with health professionals based in this province.

Each time a cadaveric kidney becomes available, a computerized algorithm is applied to the wait list to select an appropriate list of potential recipients for that kidney. The selection is based on the degree of match between tissue types of the potential donor-recipient pairs, the absence of an immune response by the potential recipients blood (stored and updated regularly at the transplant site) to donor cells (called a cross-match test), and the time the potential recipients have been waiting on the list. Once a suitable potential recipient has been selected, a call is made via the organ donor program to the potential recipient's nephrologist to ensure current medical suitability. Then arrangements have to be made by the organ donor coordinator to have the recipient travel to the transplant center. This has to be arranged at very short notice and the recipient has to arrive at the transplant center as soon as possible to minimize damage to the kidney during storage. In most cases patients travel on the next available scheduled airline flight.

Patients and donors usually remain in or near the transplant center for one to four weeks after surgery. This is to ensure stability and treatment of any early complications of the procedure. Once the recipients return to this province, all of their care is once again provided by the nephrology teams in St. John's or Corner Brook. Rarely a complication occurs that requires the recipient to return again to the transplant center for care.

Reimbursement Systems for Patient-Associated Costs of Transplantation

Organs transplanted from other people tend to be rejected by an immune response to the foreign tissue in the recipients. To prevent this and prolong the functioning of the transplant, immunosuppressive drugs are given for the life of the transplant. The drugs are taken by mouth, usually on a daily basis. Generally two or three drugs are given in combination to maximize effectiveness. The doses are carefully controlled and drug levels monitored to minimize the potentially serious side effects. Prior to the mid 1980's the combination of steroids and azathioprine was used for virtually all patients. In 1985, with the advent of cyclosporine, there was a major reduction in rejection rates and more transplanted organs continued to function for at least 5 years. The cost of cyclosporine was (and remains) high. Around that time a program of universal coverage for this medication for transplant recipients was set up via a central provincial pharmacy system. This system has since been disbanded, but the drug remains available without charge through several hospital pharmacies in the province. Over the past five years or so, other drugs have been added to the mix that can be used to prevent rejection. Mycophenolate mofetil has largely replaced azathioprine for new transplants. Tacrolimus has been used in place of cyclosporine in some cases. Most recently rapamycin has been used in conjunction with low dose steroids and tacrolimus for some patients. All of these newer agents cost about the same as cyclosporine. The total cost per patient remains controlled by the fact that only two of the more expensive agents are likely to be used for a patient at any given time. Research into the optimal combination of drugs, the doses to use, and when some can be withdrawn is ongoing. In the meantime patients now end up on a variety of drugs for varying periods. As discussed below, with modern management there has been a steady improvement in the rates of rejection and survival of the kidney transplants. This is partly as a result of this improved immunosuppressive approach. The cost of the newer immunosuppressive agents is generally borne by hospital pharmacy budgets, as has been the case for cyclosporine.

Because solid organ transplantation is not available in this province, patients are entitled to have aspects of their care paid for through a variety of mechanisms. The costs of medical care, both in the hospital and in the immediate post-transplant period are largely covered by an agreement negotiated between this province and the transplant center. The charge per case has remained constant at $19,500 over the period 1997/8 to 2001/2. The following table summarizes the number of cases and the amounts paid by the province for these services in the past few years.

Table 1 : Number of cases and total annual charges for out-of-province medical care of kidney transplant recipients 1997/8 to 2001/2

	1997/8	1998/9	1999/00	2000/1	2001/2
# of Cases	22	19	25	32	34
Total Paid ($)	429000	370500	487500	624000	663000

In addition to the cost of medical care, transplant recipients and their donors may be eligible for financial assistance with the cost of travel to receive the transplant. A Medical Transportation Assistance (MTA) program, first implemented on 1 April 1998, applies to those not receiving Social Assistance. This program has provided assistance to 41 people (48 travel claims as some cases were assisted on more than one occasion) over the period 1998/9 to 2002/3, with the total cost to the province being $61,309. This amounts to an average of $1,277 per travel claim. To be eligible for assistance under this program a person must be referred by a physician for an insured service not available in the province and the cost of an escort is also considered if recommended by the physician. Eligible expenses under this program include tickets on a commercial airline, taxi fares, a per diem allowance for accommodation and meals. A $500 deductible is applied and then 50% of remaining expenses may be reimbursed up to certain item specific limits. The reimbursement amount is reduced if the claimant has partial coverage from a private insurer.

The MTA program excludes those receiving Social Assistance, whose eligible medical travel costs are funded separately by the Department of Human Resources and Employment. Reliable data for transplant associated assistance amounts were not available from this source.

Trends in Recipients, Donors and Wait List

The following table shows the total number of people with functioning kidney transplants, or on any type of dialysis on December 31st of each year. The data were derived from estimates published by the Canadian Organ Replacement Register (CORR). The data show a slow, steady growth over time, with the number on dialysis growing more quickly than the number with functioning transplants. No data have been published yet for more recent years, but the trends are likely to continue.

Table 2: **Number of patients on dialysis or with a functioning transplant at year-end in this province.**

	1997	1998	1999	2000
# With Transplants	237	244	254	264
# on Dialysis	238	248	275	300

CORR data also indicate that anywhere from 75 to 128 kidney transplant operations overall were carried out annually in Halifax between 1992 and 2000. These numbers include transplants from cadaveric and living donors.

The CORR preliminary report for 2002 indicates that there were between 9.3 and 19.5 organ donors annually from each million people living in Atlantic Canada over the period 1992 to 2000. The lowest rate was in 1998. In 2000 the rate was 18.9 per million, equivalent to 45 donors (from whom up to 90 kidneys would be expected). The donation rate in this province has also varied considerably over time. A targeted effort was made in 1998 to enhance the awareness and capacity at all regional hospitals across the province around potential donor recognition, approach to families concerning donation, and donor medical management. This was on a background of ongoing efforts to maintain community awareness and knowledge in this field. Fortunately, these efforts have been associated with this province having the highest donor rate in Canada for the past 3 years. The rate has been around 28 per million of population here over that time frame. The actual number of donors can be less than the number of potential donors, if the donation process is not handled efficiently. Problems can occur at any step along the way, including arranging retrieval and engraftment in a timely manner. In the Atlantic region as a whole in 2000, there were 59 potential, but only 45 actual donors. Smooth functioning of the organ donation process is therefore key to ensuring success of the entire enterprise.

The following table using CORR data shows the number of people waiting at each year-end for a kidney transplant in the Atlantic region between 1992 and 2001.

Table 3: Number of patients waiting for a kidney transplant in Atlantic Canada by year

1992	1993	1994	1995	1996	1997	1998	1999	2000	2001
202	193	158	213	233	233	202	271	213	192

Should there be a Kidney Transplantation Program in Newfoundland & Labrador?

Kidney transplantation has been available in this province in the past, but not for many years. About 24 patients per year from the province receive kidney transplants. Most of the transplant surgeries are done in Halifax, which is the closest transplant centre. A few transplants, mainly with living donors, are done in Toronto or elsewhere, because the donor/family choose the more distant site for their convenience. About one or two of the 24 recipients may receive combined kidney/pancreas transplants. If a program were developed in this province, these latter two groups of patients would continue to be transplanted out of province. This would leave about 21 kidney transplant recipients per year who might be transplanted in Newfoundland. These would likely break down to 12 cadaveric and 9 live donor transplants.

The major advantage to having transplant operations done in this province would be the easier access for patients and families to the transplant centre. There would not be a need to arrange out of province transport at short notice for cadaveric recipients. This can be very costly if it involves air ambulance transport. It would probably be easier for the families of many donors and recipients to visit, or accompany those having surgery if this was being carried out in Newfoundland. For those patients and families who are eligible for government assistance, the cost of transportation would be less within the province than if travel between provinces was necessary. There could also be some spin-offs to developing the capacity to transplant patients locally. These include enhanced health care provider skills for the care of patients with kidney and other transplants. In addition, it is likely that a greater focus on transplant related research would occur in this province if a transplant centre were located here. It is unknown whether the currently favourable organ donation rates would be higher if a transplant program operated in the province. The fact that donation rates are higher here than in Nova Scotia, where transplantation currently occurs, argues against such an increase in donor rates.

There are several negative aspects to developing a transplant program in the province as well. The volume through the Atlantic program in Halifax would obviously decline by about 25%. The Atlantic program is currently among the largest in the country and has enjoyed good results. A group of skilled and experienced providers exist in Halifax. It is uncertain whether similarly good results would be obtained with a Newfoundland based program, at least at the outset. It is possible that loss of part of the program from Halifax would lead to loss of staff and skills at that site, with a consequent adverse effect on capacity within the region as a whole. A program in Newfoundland would be small. It would tend to be critically dependent on one or two individuals for successful operation. Such a program would be vulnerable to unanticipated staff changes, which have a history of happening in Newfoundland.

The administrative requirements to meet and document compliance with standards will be similar irrespective of program size. This means that regionally there will be increased resource used for administrative relative to clinical purposes. This may not be such a big disadvantage if the laboratory standards (for tissue typing and cross matching), in particular, are currently being met and documented.

It is likely that there would be a negative reaction in Halifax to development of a transplant program in Newfoundland. This could pose difficulties for the currently good relationship between providers in Halifax and Newfoundland. It is unclear whether this would affect access to care for patients from this province needing transplantation in Halifax.

Currently kidneys retrieved from donors in the region are shared via the Halifax site. It would be preferable to continue regional organ sharing even if a transplant program was developed in this province. However, over the years Newfoundland and Labrador has varied from being a net donor to a net recipient of organs under the sharing arrangement. It is not clear what impact this variation would have in the long term on the operation of a program in this province. However, the success of the organ procurement organization would be crucial to the ongoing operation of a local program.

Several specific types of resources would be needed to support a transplant program in this province:

Human Resources: While urologists working in St. John's have performed renal transplantation surgery, another urologist with specific recent training and experience in kidney transplantation would need to be recruited. Similarly there would be a need to recruit a nephrologist with specific training and experience in kidney transplantation. There appear to be adequate existing staff resources in the Transplant Clinic, Diagnostic Laboratories, Diagnostic Imaging, and the Operating Room to accommodate a program.

Kidney transplant recipients would require care in a special area staffed by one R.N. for the first two post-operative days. This nurse would be able to manage two recipients at the same time, or one recipient and up to two non-transplant patients in the same room. After the first two days, recipients would require about 4.5 hours of nursing time per day. Average length of stay would be about 10 days. This leads to a projected need for 60 hours of nursing time per case for in hospital post-operative care. The annual total for a program would be about 1260 hours. Live donors would each require about 4.5 hours of nursing per day for four days.

Space & Facilities: There is adequate existing space in the ambulatory setting for nephrology to accommodate the program. There would be an increased demand on the Hostel at the Health Sciences Centre in St. John's to accommodate patients and family members in the post-operative period. This is projected as 14 days per case for family and four days per case for patients. This amounts to a total of 378 room days per year (or an average of one room occupied all the time) to support the program.

The transplant surgery would be carried out electively with living donors. This would require two operating rooms simultaneously (one for donor nephrectomy & one for the recipient) at the Health Sciences Centre. This would be expected to occur about nine times per year. Live donor nephrectomy and transplant placement each usually take about three hours in the O.R. With cadaveric donors, only one O.R. is required per recipient, but there might be two recipients simultaneously if both kidneys were placed within the province. Placing cadaveric transplants in a timely manner would require bumping some patients already scheduled for operation. The impact would not be major if only about 12 cadaveric organs were transplanted per year.

Recipients would need to go to a special care area post-operatively for the first two days or so. This would be the equivalent of one four bed unit at the Health Sciences site, set up to accommodate two recipients simultaneously. The reason for the space is to accommodate the supplies, equipment and personnel needed for early post-operative care. In situations where only one recipient was being cared for at a time (likely with living donors, or sharing of cadaveric kidneys between provinces), the unused space could be used to care for two regular ward patients. Similarly when there are no transplant recipients in the hospital, the overall space could be used for up to four regular ward patients. Live donors would be expected to be cared for on the Urology ward.

The incremental cost of operating a transplant program in this province is difficult to determine exactly. A review in 1998, using the above assumptions about how a program might function, came up with an operating cost of about $200,000 per year. This did not include physician charges, administrative costs or the costs of training etc. The charge for 21 cases transplanted in Halifax would be $409,500 and this is probably closer to the true cost of operating a program in this province.

Current and Potential Problems

Treatment facilities for end-stage kidney disease have recently been more dispersed across the province, with the development of new and satellite haemodialysis units. This trend has increased the expectation on the part of the public and patients that they will receive all needed care for advanced kidney disease nearer to home. Indeed, patient's willingness to travel may be reduced when at least one treatment option is available near to where they live. As discussed elsewhere in this report, people approaching end-stage kidney disease need to be seen and assessed by specialized multi-disciplinary teams in order to determine their suitability and their preference for the various treatment options, including transplantation. This implies a need to have these services accessible to patients living in areas of the province remote from St. John's and Corner Brook, where the services are currently concentrated. Resources are needed to develop the education and assessment capacity at regional sites in support of the outreach medical nephrology services already provided; otherwise, there may be a detrimental underutilization of transplantation, and indeed home-based dialysis therapies, for patients in these regions.

OPEN program staff indicate some recent difficulties in organ retrieval in this province. Since the Halifax program stopped transplanting liver and pancreas, there has been a greater reliance on teams from more distant regions of the country to come and retrieve multiple organs. In cases where it seems likely that kidneys, but not other organs, will be available for transplantation, there has been greater reliance in recent years on having the retrieval performed by staff from within this province. Indeed health care professionals from this province are integral to the organ retrieval process in most cases. These professionals include anesthesiologists and surgeons, especially urologists. Such fee-for-service providers currently bill MCP for their services using fee codes for procedures, such as simple removal of a lung, which underestimate the work involved in dealing with a cadaveric donor. The absence of a specific payment mechanism for this work is a deterrent to their involvement in the process.

There is no clear mechanism to have new immunosuppressive medications reviewed for potential provision free of charge to transplant recipients in a manner similar to cyclosporine. It would be inappropriate to have universal coverage applied only to cyclosporine now that alternative agents have been shown to provide at least as good results. Similarly, it would make no clinical or financial sense to limit access to immunosuppressive agents for transplant recipients, given the medical and economic advantages of this therapy for end-stage kidney disease. A clear mechanism is needed to have new immunosuppressive medications reviewed for coverage. This mechanism needs to apply to across the province, with decisions made linked to appropriate financial resources.

The "working poor", who fall just short of meeting criteria for social assistance programs, are disadvantaged by the cost of travel out-of province to access transplantation services. In particular, the need to travel at short notice on commercial carriers at high fares, poses great financial challenges for such people. While the MTA program offers limited assistance after the fact, there is a great need for a more immediate form of financial assistance at the time patients receive a call to travel out of province for immediate transplantation.

Module F

Institution and Community Based Satellite Haemodialysis Units: A Comparison of Models in Stephenville and Clarenville

Institution and Community Based Satellite Haemodialysis Units:

A Comparison of Models in Stephenville and Clarenville

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Executive Summary

In March of 2000, the Department of Health and Community Services (DOHCS) announced that it would provide funding for the establishment of a satellite haemodialysis unit in Clarenville. This action signified a commitment to the decentralization of health services in this province and a commitment to improving the lives of individuals in the region requiring haemodialysis services. Providing the dialysis service in Clarenville necessitated a partnership between Eastern Health and Community Services Board (EHCSB) and the Health Care Corporation of St. John's (HCCSJ). A Memorandum of Understanding (MOU) was drafted which indicated that EHCSB would be administratively responsible for the unit, while HCCSJ would provide the medical expertise. To direct the development of this service, a Steering Committee was instituted with members from DOHCS, EHCSB, and HCCSJ. This committee established goals and objectives for the unit and set forth to carry them out. A key component of the program was that it be evaluated after a year of operation to ascertain the extent to which it was meeting its goals and objectives. It was asked that the evaluation also examine the implementation and development of the unit, and provide recommendations for the future of the Clarenville unit and for the establishment of units elsewhere in the province. On July 23, 2001, the Clarenville dialysis unit opened its doors – a seven-month delay from the proposed date of December 2000.

Around the same time, action was being taken by community activists on the West Coast of the Province to establish a satellite dialysis unit in Stephenville at Sir Thomas Roddick Hospital (STRH) under the direction of the Western Health Care Corporation (WHCC). The development of this unit was to involve a committee composed of individuals of STRH and Western Memorial Regional Hospital (WMRH). STRH was to house and provide administrative support for the unit while WMRH was to provide medical expertise and nephrologist support in collaboration with dialysis-trained internists at STRH. In the interest of comparing the community-based unit in Clarenville to an institution-based unit, DOHCS initiated an evaluation of the STRH satellite unit. An evaluation committee composed of representatives of the DOHCS, STRH and WMRH was organized and goals, objectives and indicators were developed for the unit. As with the community-based satellite, it was asked that the evaluation examine the process by which the unit was developed and implemented.

The present report is a comparison not of the two satellite units as such, but of the distinct modes of service delivery – community-based vs. institution-based. The findings of the evaluations indicate many advantages and positive aspects of both models of delivery as well as a variety of challenges faced by the units.

Presented here are lessons learned over the first year of operation of the units. While there is no clear indication that one model is superior to the other, several elements of the service delivery were found to be facilitated by one model or the other. It was found that the institution-based unit had better access to lab, social work, dietetic, and laundry services and to a larger pool of nurses who could be trained to provide relief (although relief staffing remains a challenge for both units). The community-based unit on the other hand was identified as being more spacious and more easily accessible and allowed patients to receive treatment in a setting that guarded them from frequent interaction with severely ill patients.

Recommendations regarding the development of a best practices document, provincial coordination, and the development of future satellite units are provided.

Recommendations

1. Evaluate both dialysis units after another year of operation.
2. Develop guidelines and policies regarding backup staffing for satellite units.
3. Establish policies and guidelines for management of community and institution based units.
4. Establish guidelines regarding nephrologist visits to satellite units.
5. Establish guidelines for the provision of biomedical services to satellite units
6. Ensure thorough research and planning regarding the location of satellite units are conducted.
7. Coordinate renal services provincially via the establishment of a renal coordinator position.
8. Postpone the development of additional satellite units until an effective service model has been established.

Introduction

Acute renal failure is a loss of the kidneys' ability to excrete wastes, concentrate urine, and conserve electrolytes. When the kidneys can no longer perform these functions (End-Stage Kidney Disease; ESKD), a person basically has two options: transplant or dialysis. Dialysis is a method of removing toxic substances from the blood when the kidneys are unable to do so. Dialysis can be administered through either a catheter placed in the abdomen (peritoneal dialysis) or through a machine (haemodialysis).

Dialysis in Canada[1]

Fast facts:

- More than two million Canadians are affected by kidney disease or related disorders.
- Kidney disease ranks sixth among diseases causing death in Canada.
- Every day, twelve people in Canada learn their kidneys have failed.
- The number of individuals with ESKD (both transplant and those on dialysis) increased from 5,549 in 1981 to 23,601 in 1999
- It is estimated that by 2006, 40,000 patients will require dialysis in order to live, at an estimated annual cost of $2.4 billion

In Canada, there has been a growth rate of approximately 9-10% in the number of individuals that require transplant or dialysis. In 2000 there were 14,567 dialysis patients with ESKD in Canada. Compare this to 1991 when the figure stood at 6,811 and we see the dramatic increase. Even more astounding is the fact that 4,386 new patients started treatment during 2000, which is 60% more than in 1991.

Of the new patients on dialysis, 38.5% were 70 years of age or older, which is a 13% increase from a decade before. Over two-thirds (69.4%) of these patients had diabetes and/or cardiovascular disease, both of which have been reported as the two primary causes of renal failure. Of the dialysis patients being treated as of December 31, 2000, 37.8% were 70 years old and 64% had diabetes and/or cardiovascular disease as either the cause of the disease or a complicating condition. The Canadian Institute for Health Information (CIHI) infers from this that compared to 10 years ago, dialysis patients today are older and sicker. This is consistent with the common conception that our population is aging. In fact, a report published by the Conference Board of Canada in 2001 indicates that the proportion of Canadians over the age of 55 will rise from 22% of the population to 32% of the population by 2020.

Dialysis in Newfoundland and Labrador

The growth rate of ESKD in Newfoundland and Labrador parallels that of the rest of the Canada. However, a major difference exists in terms of the age of Newfoundland and Labrador's dialysis patients. CIHI reports that during 2000 Newfoundland and Labrador had the highest rate of new patients who were aged 70 years and over. CIHI also report that as of December 31, 2000, Newfoundland and Labrador had the second highest rate per 100,000 population of dialysis patients.

In Newfoundland and Labrador, haemodialysis has been available in St. John's for many years. In 1974, a dialysis unit was opened at Western Memorial Regional Hospital in Corner Brook and the population there has grown over the years. In early 1998, a unit was opened in Grand Falls-Windsor providing haemodialysis service for much of the central part of the province. These services are hospital based with no specific limitation on the kind of patient able to access these services. The renal services in St. John's are considered to be tertiary care and provide backup for the patients in both Corner Brook and to a greater extent, Grand Falls-Windsor. In July of 2001, haemodialysis units were opened in both Stephenville (July 9) and Clarenville (July 23).

Table 1

Number of Dialysis Stations and Patients for Haemodialysis Sites in Newfoundland*

Location	# of Stations	# of Patients
St. John's – Waterford	34	114
St. John's – HSC	16	38
Corner Brook	14	48
Stephenville	4	12
Grand Falls-Windsor	15	41
Clarenville	4	6

*Numbers are based on information reported to the evaluators in February 2003.
*It should be noted that Stephenville and Corner Brook share three patients.

Clarenville

The unit that was opened in Clarenville is unique to this province in that it is not located within, or administered by a hospital. The unit is under the administration of EHCSB but the HCCSJ provides the medical direction.

The unit in Clarenville opened its doors July 23, 2001 – a seven-month delay from the proposed operational date of December 2000. The primary reason for this delay was the need for research and planning; this was a different model of service delivery and the first of its kind in this province. An announcement in the 2000 budget speech got the ball rolling for the unit. The decision to develop satellite units in the province was based on a report produced by the Provincial Renal Advisory Committee (PRAC) in 1999 and a large amount of public advocacy; each of which supported a need to decentralize dialysis services. The PRAC report provided evidence suggesting that the populations of dialysis patients in several regions of the province could sustain dialysis services. As is indicated in the findings, the majority of individuals involved with the unit were uncertain as to how the unit originated. The only factors that were mentioned were the PRAC report and public pressure. After the unit was announced, research and planning were implemented to decipher how the project should proceed. The first questions to be asked were who would be administratively responsible for the unit, and where would it be housed. The question as to where it would be housed dictated administrative responsibility. Representatives from . Peninsulas Health Care Corporation (PHCC) indicated that there was no space available at the Dr. G. B. Cross Memorial Hospital; however, EHCSB were about to tender for the construction of new office space and indicated that space for the unit could be included in the plans. Another factor in this decision was the concern of the chief nephrologist of the dialysis division of HCCSJ regarding the expectations of patients concerning the level of care available if the unit was housed in a hospital. It was indicated that the public might not understand that the hospital in Clarenville is not equipped to effectively manage unstable dialysis patients. Additionally, there were concerns that the doctors in Clarenville might feel obligated to treat the dialysis patients, when their expertise may not be in the field of nephrology.

Following the decision to place the unit in the administrative care of EHCSB, the need arose to establish guidelines for the implementation of the unit. Subsequently, three members of the Steering Committee conducted site visits to satellite units in Nova Scotia and PEI. These visits provided the committee with valuable information that could be transferred to the development of units in this province. These visits, combined with guidance from HCCSJ, provided the information necessary to begin planning construction of the unit. Such research triggered the realization that the December 2000 start date was not realistic. The original budget underestimated the cost of staffing the unit and the cost of a water treatment system. Further, there were no funds allotted for the design and construction of the unit; therefore, requests had to be made of DOHCS to secure additional funding. The department recognized and supported the financial needs of the unit.

Stephenville

The unit in Stephenville, although based in STRH, is a satellite unit of WMRH. This means that the access to the unit is restricted to those that are medically stable and nephrology services are provided from Corner Brook.

An identified need for dialysis service in the Stephenville area is not a recent phenomenon. It was noted that there had been some discussion regarding the feasibility of developing a dialysis service in Stephenville in 1996; however nothing happened at that time because of a lack of internal medicine coverage. The need to develop the unit became somewhat paramount in the late nineties when the dialysis service at WMRH was facing the need to expand and dialysis patients were voicing their desire for a unit in Stephenville. Certain individuals in the community began raising funds to donate to the hospital in support of a unit. The push from the community came through the District Advisory Council and the STRH Foundation. The STRH Foundation contacted management at STRH and indicated that fundraising was occurring for a dialysis service. At the same time, management with WMRH were indicating that the dialysis service in Corner Brook was reaching its peak and if Stephenville didn't develop a unit, then WMRH would have to expand their service. Such issues were taken to the Senior Team of WHCC and this group agreed that something would need to be done. From this point forward a mass of information was collected to ascertain if it would be feasible to develop a unit in Stephenville. The collected information was compiled into a proposal supporting the establishment of dialysis services in Stephenville and subsequently approval to begin development was granted by WHCC. Following this approval, key individuals were brought together from STRH and WMRH on Oct 27, 2000 to form the Steering Committee for the project. A Terms of Reference was accepted for the Steering Committee on November 24, 2000, which stated that their purpose was "to oversee the successful expansion of the Regional Renal Dialysis Program such that a satellite service be developed and introduced at the STRH site." As the unit was to be a satellite unit under the medical direction of WMRH, a working relationship had to be developed between STRH and WMRH to ensure efficient and effective service delivery.

At a meeting of the Steering Committee, that occurred on December 18, 2000, it was agreed that the target date for opening the STRH dialysis unit would be June 1, 2001. The unit in Stephenville opened its doors July 9, 2001; a small delay from the proposed date noted above. It appears the delay in opening the unit was primarily the result of a lack of internal medicine coverage during the month of June. The reason for this is a combination of internist leave and nephrologists with WMRH not being available to provide training. Also contributing to the delay were problems incurred with obtaining equipment for the unit. There was a delay in receiving both the reverse osmosis machine and the chairs for the unit. It was noted in the minutes of June 15, 2001 that all construction had been completed on the unit.

Evaluation

The Evaluation Committees for the Clarenville and Stephenville units developed an evaluation framework for the project and selected the consultant, Panacea Research & Evaluation, to complete the evaluations. A key aspect of this evaluation is that it was completed with a high degree of collaboration between Panacea Research & Evaluation and the Evaluation Committee, allowing the evaluation to occur efficiently and effectively.

Model Comparison

Preparation of a program for meaningful evaluation can be a daunting and time-consuming task; however, this process is facilitated by preparing for evaluation throughout all stages of a program from planning and development to implementation and operation. The formation of Evaluation Committees for the units has greatly enhanced the evaluation process by providing the consultants with a team of knowledgeable individuals. This ensures that the evaluation will inform decision-making concerning the management of the units in Clarenville and Stephenville, and the possible development of other units throughout the province. Subsequent to this evaluation, changes may occur in the administration of the units that may alter unit organization and service delivery. As such, the programs should be monitored closely by the Evaluation Committees to ensure that information is maintained for efficient and effective evaluation. It is recommended that evaluations occur after another year of operation.

Human Resources

Staffing

Front line staffing issues were found to be one of the biggest challenges for both satellite units, and it is expected that such issues will again surface in future endeavours. Although at first glance solutions to the issue of staffing the units seem simple, the matter is actually quite complicated. There is a fine line between the unit being adequately staffed and overstaffed. Staff: Patient ratios are more than adequate for both units, however, the logistics of organizing breaks when there are only two nurses on a unit can be troublesome. Both the Stephenville and Clarenville units are adequately staffed on any given day, but problems arise when more than one staff member is unable to show up for work. There seems to be no perfect solution to this particular challenge as the reason the issue has arisen at all is likely due to the nature of the nursing task. Dialysis nursing is extremely specialized and a skill that must be practiced if competencies are to be maintained. It is therefore not enough to train a pool of nurses who can be called upon when necessary for backup support unless this pool is able to practice their dialysis skills regularly.

Both units have relied on staff of the parent units for backup at some point since opening. While this is acceptable in cases of emergency, it is not a practical solution to the staffing issue given the geographical distance between the satellite and parent units. EHCSB attempted to remedy the human resource issue at the Clarenville unit by hiring a nurse for a shared position with Community Health programs; however, the position has not worked out as initially planned. The nurse in this position is working in two completely different fields and has a commitment to both teams of nurses. It is difficult for her and for her Community Health nurse co-workers when she is called from a scheduled activity to cover a shift in the dialysis unit.

It was suggested by the evaluators at the time of the evaluation of the Clarenville unit that a number of avenues be explored in addressing the staffing issue. Specifically:

- Strengthen the partnership with PHCC such that training may be provided to several nurses of Dr. G.B. Cross Memorial Hospital, thereby providing a larger pool of nurses to pull from in the event that adequate staffing is not available for the unit.
- Provide additional services to individuals with various levels of renal failure through the Clarenville dialysis unit. The offering of additional services would justify and warrant an additional fulltime nursing position.

It should be noted that these are not foolproof solutions to the staffing issues in Clarenville. As previously noted, dialysis nursing requires that skills be practiced on a regular basis if competency is to be maintained, therefore, it may be difficult to keep up the competencies of any nurses trained at PHCC unless they were given regular shifts at the dialysis unit. This could be a problem given that nurses of EHCSB and PHCC are involved with separate unions and receive different rates of pay based on classification levels.

Providing additional services at the unit, such as pre-dialysis education, might be an option for the Clarenville unit if the population base in the area is such that it warrants these services. The offering of additional services would justify and warrant an additional fulltime nursing position. Before such an option is put into action it is suggested that a review of population trends over the last five years for dialysis patients in the area be conducted.

The STRH satellite unit has also experienced staffing problems since opening. Findings of the evaluation report indicate that when staffing has become an issue, the satellite unit has dealt with the problem by recruiting staff of WMRH to cover the shift. However, there is no policy in place at the present time that dictates that WMRH staff are required to cover shifts at the STRH on their day off. Given the distance, and the treacherous road conditions at times, it is unlikely that the STRH unit will always be able to rely on WMRH to provide backup every time the unit is understaffed. Therefore it is necessary that other options be explored.

One suggestion made by the evaluators was that the possibility of running a six machine unit as opposed to the current four machine unit, as it was felt by various key informant groups that this would allow more efficient scheduling of dialysis appointments and staff shifts.

It may also be feasible for STRH satellite unit to rely on a pool of trained casual nursing staff for backup staffing. The unit currently has at least one trained casual dialysis nurse and one trained float nurse to provide backup. Training additional float and/or casual nurses may resolve some of the human resource issues faced by the STRH unit if it is possible for the unit to ensure that the float and casual nurses work on the unit frequently enough that their competencies are maintained.

Unfortunately, neither report was able to suggest an all-encompassing solution to staffing issues that arise with satellite dialysis units. One possible solution is the employment of paraprofessionals such as LPN's, as is done in other provinces. It is suggested that a fundamental aspect in developing a best practices document for satellite dialysis units in the Province should be the production of guidelines and policies concerning backup staffing for the units.

Management

There have been challenges concerning the management of both the Clarenville and STRH dialysis units; however, the challenges faced by each unit have varied somewhat. For the community based dialysis unit, there have been both administrative challenges and those concerning renal knowledge from a management perspective. One of the biggest challenges for EHCSB was that their managers are educated in community health programs and have no experience with, or exposure to, renal dialysis settings. Although these managers are quite capable of providing administrative support, the provision of clinical support has been difficult because they have to rely on external sources for monitoring nursing practices. One external source that has been utilized extensively is the division manager of dialysis units of HCCSJ.

Challenges related to managing the STRH unit have not been as a result of unfamiliarity with renal care and dialysis, but rather to the time constraints of the manager of the unit and the loss of a team leader for the unit. While the manager of the STRH unit has made every effort to be available to the unit on a regular basis, at the time of the evaluation this individual was occupying another position on a temporary basis and the individual's time was therefore thinly spread. This led staff of the unit to feel that their manager was somewhat inaccessible and that they were not receiving as much attention from their unit manager as they should. This was exacerbated when a staff leader with a great deal of experience and knowledge of dialysis left the unit to obtain employment elsewhere. This meant that all staff left on the unit were new to dialysis nursing and somewhat hesitant in dealing with situations they had not previously encountered. One of the nurses took on a temporary role as team leader for the unit, however, findings of the evaluation indicate that nurses of the STRH unit felt that a decision should be made regarding who would lead the team of dialysis nurses on a permanent basis. Staff suggested a number of options including a rotating team leader and a permanent leader with a great deal of dialysis experience. Patients of the STRH unit and staff of WMPH indicated that they would like to have one individual in charge of the unit so that they would know to whom they should address any issues or concerns regarding patients' care or the unit in general.

It is suggested that the challenges of unit management, which were prominent in the evaluation of the Clarenville and STRH units, be addressed prior to the establishment of any future satellite units. Guidelines and policies for adequate management need to be established for both community-based and institution-based satellite units. The feasibility of recruiting managers at both the unit and team level with considerable dialysis experience should be assessed.

Nephrologists

A number of challenges regarding nephrologist care and visits were revealed by the evaluations of both the community-based and institution-based units. It was indicated by informant groups of both units that planned nephrologist visits to the sites were not always carried out as scheduled. Nephrologist support is provided to the satellites by their respective parent units, and staff and patients of both sites felt that nephrologist follow up should be available to patients on a more regular basis. While both units have developed policies pertaining to the frequency and regularity of nephrologist visits, it is obvious that these policies are not being adequately adhered to at the present time. Time constraints, inclement weather, and other commitments were some of the reasons indicated by informants for scheduled nephrologist visits being cancelled or postponed.

In some cases patients of the community-based unit have gone as long as six months without a visit from the nephrologist. However, the nephrologist assesses each patient's status regularly through the use of the Nephrocare computer system. Prescriptions may be changed, treatment regiments altered and advice may be given to frontline staff pertaining to the care of the community-based satellite unit patients via this system. Given the stability of the patients, this sort of long distance care for patients is likely sufficient. That being said, it is imperative that patients visit with the nephrologist in person on a regular basis. Staff of the community-based unit felt that it was also important for the nephrologist to visit the unit itself more often. At the time of the evaluation it was noted that patients of the Clarenville unit met with the nephrologist at Dr. G.B. Cross hospital during clinics that were scheduled not just for the dialysis patients, but also for patients with a variety of renal ailments. However, it was also noted that because patients of the unit arrive for their dialysis treatments at different times throughout the day, it would be difficult for the nephrologist to travel back and forth between the hospital and the satellite unit several times per day. Therefore it was deemed that holding clinics at the unit itself was likely not feasible. Based on these findings, it was recommended that nephrology support be formalized and physicians be held accountable.

The evaluation of the community-based unit also revealed a concern by staff and physicians regarding proper medical care for patients of the satellite unit. It was noted that because there is no nephrologist in the area, it is possible that if a dialysis patient of the community-based unit is admitted to hospital for an emergency, physicians who have not received the necessary training for treating dialysis patients would be forced to tend to the patient without the necessary knowledge to best treat the patient. This finding resulted in the evaluators recommending that the physicians at Dr. G.B. Cross Memorial Hospital receive information sessions from nephrologists regarding the care of dialysis patients.

The issue of untrained physicians providing care to patients was not a concern for the STRH unit as there is a trained internist on staff who is available almost any time. The hospital has also in hired a second internist who has received dialysis training and will therefore be able to provide assistance in the care of the dialysis patients. However, as noted above, key informants of the STRH unit did cite some challenges regarding the frequency and regularity of nephrologist visits. While minutes of meetings indicate that during planning stages for the unit it was decided that patients should receive visits from an internist during each dialysis treatment and a visit from the nephrologist once per month. Patients of the STRH unit indicated that since they began receiving treatment at the unit one of the things they missed most about receiving treatment at WMRH was the regular contact with the nephrologist. It is the opinion of the patients that such regular contact better ensures that their requests concerning their care are better followed up on when they are able to meet with the nephrologists, whether this is in fact the case is unclear.

Whether this was a major problem in the eyes of the patients varied somewhat. Most noted that they were able to have contact with the internist during each visit and felt that this was sufficient as it was their opinion that the internist for the satellite unit is extremely competent and able to deal with a variety of issues without consulting with the nephrologist directly. Additionally, patients noted that weekly reports were sent to the nephrologist for review and that they felt that this was sufficient because they are receiving treatment from a satellite unit and therefore they are stable and do not require the same level of interaction with the nephrologist as less stable patients might.

This leads us to another issue identified by the evaluation of the STRH satellite unit. The evaluation indicates that the unit is currently operating with one full cycle of dialysis patients and two-thirds of a second cycle, with the remaining third of this cycle being fulfilled at the WMRH unit. The reason for this is that the unit cannot operate on Saturdays as there is only one trained internist at the hospital and it is unreasonable to expect that this individual be on call every weekend. Item eleven of the Admission and Follow-up Criteria for the STRH dialysis unit indicates "there must be an internist available on staff to visit the patient on dialysis each treatment." This requirement has prevented the STRH dialysis unit from servicing patients on Saturdays and expanding to a six-day service. Further, minutes of the Renal Care Performance Improvement Team (RCPIT) meeting held on February 19, 2002, reflect that it would be preferential if there could be two internists working at STRH before Saturday service commences. It was reported to the evaluators that there has never been a period since the unit has opened that there hasn't been a medical internist on site while patients are dialyzing.

A number of key informants suggested that it might not be entirely necessary for the unit to have daily coverage by a medical internist. It is understood that the requirement to have internal medicine support for the unit originates from the desire to provide the same quality of care at STRH as would be received at WMRH; i.e., patients are guaranteed a visit by an internist. This is problematic for the unit as it was decided that internists who would monitor the satellite unit daily must be trained in Corner Brook by working with the nephrologists for two weeks on the unit at WMRH. Therefore, not only is it necessary to recruit internists to fill positions at STRH, but also to train them for their involvement with the satellite unit. Ideally, from the point of view of a number of key informants, there would be two internists in place at STRH, which would allow them to take turns being on call for the unit on Saturdays. This would allow the unit to remain open on a six-day cycle thus opening the services of the unit to more patients and allow all stable patients from the Stephenville area currently being dialyzed at WMRH on Saturdays to be dialyzed three days per week at STRH. It was noted by several informant groups that there are patients currently going to WMRH for treatment who are stable and could be good candidates for patients of the satellite unit. These individuals are unable to receive treatment from STRH simply because there is not space in the schedule to fit these patients in for treatment at the satellite unit.

This evaluation has revealed that the initial staffing for the institutional-based unit was too high and was reduced to reflect the stable nature of the patients. It was therefore recommended by the consultants that the necessity of requiring a medical internist to be available to dialysis patients be evaluated. To permit the nephrologists at WMRH to more effectively care for and monitor the STRH patients, it is recommended that a computer link, similar to that between the Community-based unit in Clarenville and the St. John's sites, be established between the dialysis units at STRH and WMRH. Such a system would also permit a more efficient running of the unit, in that nurses would not need to fax weekly patient information to WMRH.

Biomedical Technicians

The respective parent units have provided Biomedical services for the satellite units with few problems up to this point. For the community-based unit, the MOU signed between EHCSB and HCCSJ states that technical services would be provided for the satellite by HCCSJ for one year. Now that this year is up the MOU is about to be reopened and this is one service that is likely to be discussed at length. It was noted that the current arrangement is costly and although there were few instances when a technician was called in to make unscheduled repairs to the Clarenville satellite unit's equipment, one should keep in mind that the equipment is only a little more than one year old. As the machines age, they may need more maintenance and repair. It was suggested by the consultants that additional resources be provided to HCCSJ for biomedical services, thereby facilitating the provision of biomedical support by HCCSJ.

The provision of maintenance services for the STRH satellite unit was also indicated to be a point of some concern. Minutes of committee meetings indicate that initially STRH had hoped to hire a biomedical technician to offer technical support for the satellite unit and a number of other services (i.e. x-ray) offered at the Stephenville hospital. However, minutes of a meeting of the Steering Committee on May 18, 2001 noted that assurance was given by the biomedical services staff at WMRH that they would give priority to STRH for support for the development of the renal dialysis unit, though it was hoped that the biomedical engineer position would still be filled before the unit was opened. At the time of the evaluation, there had been no biomedical staff hired for the satellite unit and WMRH was continuing to provide this service to the STRH unit. It was noted that when biomedical support is gone to STRH from WMRH, then there is no support available to WMRH and that this situation was often uncomfortable. It was the opinion of biomedical staff interviewed that given the various equipment at STRH (i.e. dialysis, x-ray) the hospital could easily sustain a biomedical position. It was therefore recommended by the consultants that the possibility of hiring a biomedical technician for STRH be assessed. Again, expanding the biomedical services at WMRH may be a possibility if hiring biomedical staff at STRH is not feasible. However, if biomedical services are to continue to come to STRH from WMRH there should be a formal agreement drafted between the two facilities outlining specifically what services are to be provided and how.

Guidelines pertaining to the provision of biomedical services should be included as an integral aspect of the best practices model for satellite units in the Province.

Social Work and Dietetic Services

The lack of social work and dietetic services available to patients of the Clarenville unit was noted to be a concern for several informant groups. At the time of the evaluation there was no formal agreement for the provision of social work and dietetic services to the satellite unit, although these services are an important part of care for dialysis patients. The need for dialysis introduces drastic social change into an individual's life as it becomes necessary for them to spend almost 20 hours per week, in some instances, receiving treatment. As a result of the time commitment involved with the treatment, many patients end up not being able to continue working, relocating, and becoming increasingly dependent on friends and family members for support. Not only does this affect the lives of the patients but also that of their family members. Adjusting to the lifestyle changes that result from renal failure can be stressful financially and emotionally for all involved.

In addition to lifestyle changes due to increased time constraints and financial burden, dialysis patients also must deal with changes related to their dietary needs. Diabetes and cardiovascular disease associated with renal failure often dictate the need to drastically change eating habits and therefore a special diet is often necessary for dialysis patients to maintain optimal levels of health and well being. For these reasons, social workers and clinical nutritionists are integral parts of dialysis patient care management teams of HCCSJ. It was recommended by the consultants that options for providing social work and dietetic support for patients be explored and steps taken to establish these services for the community-based unit.

Although some informants for the institution-based satellite unit raised the issue of social work and dietetic support, concerns expressed were of a lesser magnitude than those for the community-based unit. Some even referred to the availability of such services on site as one of the greatest benefits of an institution-based satellite unit. Despite this, other key informant groups, particularly STRH staff and patients of the satellite unit, felt that referrals to social work staff have been lacking. Given that it became apparent during the evaluation that such services are indeed available to patients of the STRH unit, it was suggested that a process of providing information should be developed such that it is ensured that every patient is *aware* of the availability of such services and how they can be accessed.

The findings of the evaluations of the two models of satellite units that currently exist in Newfoundland and Labrador seem to point to the availability of social work and dietetic services as one benefit of an institution-based model. In developing a model of best practices this should be taken into consideration. However, it should not be assumed that such services cannot be provided in an efficient and cost-effective manner to community-based units until avenues for procurement of these services, as suggested by the evaluation of the Clarenville unit, have been explored.

The Unit

Cost

While the two satellite units share many similar financial burdens (e.g., staffing), two major differences exist (i.e., funding source and construction costs). The Clarenville unit was funded entirely by the provincial government, while the Stephenville unit was funded primarily by money donated by the community to the Sir Thomas Roddick Hospital Foundation. With respect to construction costs, the Clarenville unit required $211,775 for leasehold improvements to accommodate the dialysis unit. Alternatively, renovations to STRH to accommodate the Stephenville unit ran $31,692.

Training staff is also a significant cost for haemodialysis services. The initial training for nursing staff is generally 12 weeks and for the satellite units, this meant paying for travel to and from the parent unit (i.e., St. John's or Corner Brook), as well as accommodations and meals. For the first three nurses that were trained for the Clarenville unit, the total cost of meals, mileage, and accommodations was $15,436. For the Stephenville unit the cost of training the first three nurses was $31,682. The fact that the cost of mileage, meals, and accommodations is so large supports the contention that the possibility of providing some aspect of the training at the satellite units should be explored. Continuing education and updating skills for satellite units also requires travel to a larger center.

In terms of cost savings to patients, the evaluations of the dialysis units in Clarenville and Stephenville indicated that patients, former patients and family members felt there have been financial savings as a result of receiving dialysis treatment closer to home. Cost savings associated with meals, transportation, and lodging were indicated. As most of these individuals are seniors, the costs associated with traveling to St. John's or Corner Brook were borne to some extent by government programs. In the proposal that was developed for the STRH it was reported that at least 9 or 10 dialysis patients were traveling to Corner Brook via taxi from the Stephenville area. It was noted that a return taxi trip costs approximately $165. As patients receive approximately 156 dialysis sessions per year, this would translate into a cost of $25,740 annually. It was suggested that nine individuals may have been availing of HRE funding to support the travel, for a total cost to the government of $257,400. It was also reported that for Social Services recipients, lunch and childcare are also covered through HRE funds. Those individuals that had to pay for their own transportation were incurring a large cost.

Financial analysis of the satellite units indicates that although the initial cost of establishing such a unit is high, once in operation the cost per patient is not a great deal more than that of the parent site. One of the main objectives of satellite dialysis units, as indicated by the goals and objectives developed for the Clarenville and STRH units, is to improve the quality of life of the patient by offering dialysis services closer to home. It is obvious that the cost of providing such a service will not be less than that of having patients travel to a unit that is already established; however, it is expected that the cost-effectiveness of the units will increase over time.

Location

The evaluations of the satellite units included the opinions of key informants concerning the location of the units in terms of the town in which the unit is located, the facility in which it is housed and any opinions of respondents regarding the benefits and challenges of being institution-based and community-based.

Town

Almost all key informants of both the institution and community-based evaluations indicated that the satellite unit with which they were involved was located appropriately in Stephenville and Clarenville respectively. The reasons that key informants felt these communities were appropriate, as indicated below, were similar for both sites:

- The community is centrally located within the region and therefore accessible to a large population of individuals.
- The community is a hub and service town which individuals from surrounding areas frequently traverse to shop and run errands.
- There is a hospital located in the community.
- A small minority of individuals indicated that Clarenville might not have been the best choice to locate a satellite unit. The primary reason given for this was the small number of patients that are being dialyzed at the unit. Although all agreed that Stephenville was the most appropriate location for a satellite unit within the region, several respondents noted that there were quite a number of patients from the Port aux Basques area who still have to drive 2.5 hours to and from their dialysis treatment. Respondents noted that Port aux Basques too has its own hospital and likely has a sufficient number of patients to sustain a unit.

Building

The dialysis unit in Clarenville has been described by many as being excellent and preferable to the facilities in St. John's. There is a higher nurse to patient ratio and the patients are not exposed to the types of 'sick' patients that they would encounter at institution-based units. That being said, there were several problems indicated by key informants pertaining to the unit and the facility in which it is housed. Some difficulties encountered included the following:

- The unit operates on a different time schedule than that of other services in the building. This has led to concerns over the safety of patients and staff when patients are being dialyzed while there is no other staff in the building.
- Concerns were expressed regarding the nurses' ability to evacuate patients from the building in case of an emergency, especially given that there is no emergency exit on the unit. Also, when pallets of medical supplies are delivered, they have to be taken apart manually and brought into the unit. It was suggested by the evaluators that the feasibility of constructing a door from the outside to the unit that would serve as an emergency exit be assessed.

- Because space for the unit is leased, several informants indicated concern over what will happen when the five-year lease runs out. If the unit has to be moved it will require a sizable reinvestment, especially for the water treatment system, which is not portable.

Key informants of the evaluation of the institution-based unit noted a number of positive aspects regarding the ward on which the unit is housed, including that it was conducive to socialization between patients and that the nurses' station is located in the room where patients are dialyzed. Several respondents also noted that although it was felt that the unit is quite small, it is an efficient use of the only space available in the hospital for the satellite unit at the time of its construction.

There were several concerns raised however. The distance from the main entrance to the unit is very far for dialysis patients to walk. When coming in for treatment, patients are generally carrying a great deal of excess fluid and any amount of physical exertion is extremely difficult. Following dialysis, patients are often very fatigued and again find the walk from the unit to the main entrance difficult. Several patients noted that they found it necessary to use wheelchairs to get to and from the unit.

Because the unit is so small nurses and biomedical staff have had difficulty in accessing machines given the limited space. Also there is little room for family to visit patients while they were receiving treatment. Also noted as a concern, was that there is only one washroom on the unit that is shared by staff, patients and family members. Further, there is not room for expanding the unit as it currently exists in the hospital.

Patients noted that they were uncomfortable walking through the inpatient ward to get to the unit. Patients indicated that they felt they might be in the way of staff working on the inpatient unit when they are walking to and from their sessions. Other informants felt that by walking through an inpatient ward patients are being forced to focus on illness as opposed to wellness and that the unit should be located within close proximity to other outpatient services. It should be noted that the majority of these concerns will be remedied when the unit is moved to the new hospital.

Institutional vs. Community Based Units

Key informants of the evaluation of the community-based satellite unit indicated a number of reasons that housing the unit in a hospital setting would be preferable to its current location in the Health and Community Services Building. First of all, it was noted that were the unit housed in a hospital there would be a greater availability of support for nursing staff. Secondly, laundry and lab services would be more accessible as currently blood samples and linens from the satellite unit are transferred to Dr. G.B. Cross Memorial Hospital via a local taxi service. Finally, respondents felt that being located in the hospital would lessen the anxiety of everyone involved regarding the stability and well being of patients and possibly permit the selection criteria to be more lenient so that the unit could service more patients. While several key informant groups indicated that being located in a hospital would result in patients being exposed to more sick individuals, this was of little concern to the patients themselves, who would generally feel more comfortable were the unit located in a hospital.

Informants of the evaluation of the institution-based unit also commented on the advantages and disadvantages of having the unit based in a hospital. Most respondents felt that satellite dialysis units should be placed in a hospital for reasons similar to those noted by participants of the community-based unit evaluation, including: 1) there is access to medical personnel in the event of an emergency, 2) it allows easy access to support services such as social work, physiotherapy, and dietetic services, 3) it allows less stable patients to be dialyzed at the satellite unit thus increasing the population base, and 4) staff can be cross-trained to provide support to the unit. However, positive aspects of being based outside a hospital were also noted including that a community-based unit may focus more on wellness and would allow patients to be dialyzed without being exposed to the infectious atmosphere of the hospital. Several informants noted that satellite units are rarely housed in hospitals and because the patients are stable it is not necessary to have the unit based in a hospital.

It is recommended that wherever the unit is to be housed, appropriate planning be carried out such that the unit is easily accessible to patients from both a broad geographical perspective and in terms of the facility in which the unit is housed. Communities in which satellite units are located should be easily accessible and serve a broad population base. It is imperative that appropriate research be conducted to ensure that there are sufficient instances of ESKD to warrant a unit. If findings of such research indicate that the need for expansion in the future is likely, plans for satellite units should be developed with this in mind. As such, units should be constructed in a manner that allows extra machines to be added, if deemed necessary, at a later date. The physical infrastructure of the unit should be such that patients do not have to walk long distances from facility entrances to the unit and if housed in a hospital, it is the desire of patients that the unit be located in close proximity to outpatient services. Additionally, whenever feasible a door from the outside directly to the unit would be beneficial for emergency exit, supply delivery and facilitating patient access to the unit.

Findings of the evaluations of the hospital and community-based units clearly indicate that patients would prefer that the units be housed in a hospital setting. However, in making decisions as to where units are located a host of factors should be considered. It is the opinion of the evaluators that with appropriate planning and resources (i.e., linkage via computer to parent sites and adequate staffing) haemodialysis satellite units have the potential to be effective in both hospital and community settings. That being said, if the purpose of providing satellite dialysis services is to improve the quality of life of the patients, then the preferences of the patients should be appropriately weighted to reflect that objective.

The Patient

Patient Satisfaction

Findings of the evaluation of the community-based dialysis unit indicate that virtually all key informants feel that the services provided to patients are high quality. A request to the Evaluation Committee from the consultants for documentation regarding patient complaints turned up no results; no formal complaints had been submitted since the opening of the satellite unit. During interviews with patients (both current and former) and their family members, it became clear that there were few complaints about the service received at the satellite unit. All interview participants indicated that they were quite satisfied with the service they received in Clarenville and that the dialysis sessions ran smoothly.

Likewise, a request to the Evaluation Committee of the STRH satellite unit for documentation regarding patient complaints turned up no results. In general, patients were very satisfied with the level and quality of care they received at the institutional-based unit. They indicated there was no difference in the dialysis treatment received at the satellite unit as compared to that which they received while being treated at WMRH. They noted that nurses at both units were competent and treated them with care and respect. Patients indicated that they liked receiving treatment from the satellite unit because they were able to interact with the same individuals on a regular basis as opposed to at the larger unit where weeks may pass before they encounter the same nurse or dialysis patient as on a previous visit.

Admission Criteria

Selection criteria for the community-based dialysis unit were developed by nephrologists at HCCSJ using a model that is in use at a satellite unit in Ontario. Prior to the unit opening in Clarenville, there were 12 individuals requesting to go there. Only five of these individuals met the criteria for admission and were given subsequent approval to begin treatment at the Clarenville unit. At the time of the evaluation there were four patients receiving treatment at the unit. Several patients have had to return to St. John's permanently as a result of their becoming unstable and therefore unacceptable to the unit. On at least one occasion all patients who were receiving treatment at the time of the evaluation had to return to St. John's for some reason, though several were related to medical issues that were not directly related to their dialysis. There are several patients in St. John's who, over the course of the evaluation, indicated that they would like to go to Clarenville for treatment but do not meet the admissions criteria. Patients understand when they are granted acceptance to the satellite unit that if their situation changes such that they become unstable they will have no choice but to return to St. John's for treatment. Because this is established prior to the patient deciding to go to Clarenville for treatment patients do not resist the transition back to St. John's, although some report that fear of having to return to St. John's is very stressful for them.

The selection of patients who are to be admitted to the community-based unit is a coordinated effort between HCCSJ and EHCSB. HCCSJ indicate the minimum stability of a patient that may go to Clarenville, while EHCSB dictate the maximum stability. HCCSJ selects the individuals that they feel are stable enough to be dialyzed in a community setting; however, EHCSB has the final say as to which individuals will actually be accepted. Representatives of HCCSJ indicate that they respect the decisions of the nurses and managers in Clarenville because they have gone great lengths to develop policies that they are comfortable with.

The evaluation indicated some controversy on the topic of the admission criteria to the community-based unit. Some feel that it is far too strict and that it is for this reason that patient numbers are down. However, many feel that the admission criteria are very appropriate and that it is necessary that these criteria be strict to ensure the safety of the patients. The unit is equipped with no emergency response resources on site and therefore would have difficulty responding in the event that a patient experienced any major complications. There is currently ongoing discussion concerning whether it's feasible for the unit to accept patients whose access is in the form of lines. Initially these patients were not considered as candidates for dialysis at the community-based site because the risk of running into complications is increased for patients with lines. Since this time several aspects of the unit have changed that have prompted review of this policy. It was therefore recommended by the consultants that the issue of broadening the patient base be examined.

Likewise, few problems were identified in relation to the patient selection process for the STRH unit. The nephrologist at WMRH, in consultation with WMRH nursing staff, selects patients for the satellite unit. No patient is permitted admittance to the satellite unit until they have spent a period of time receiving treatment at WMRH and have proven to be stable. There was no evidence of unstable patients being admitted to the satellite unit and overall, key stakeholders were comfortable with the selection process. However, nurses of the unit indicate they would like to be more informed of the actual process and receive more warning that a patient will be transferred to the unit. In the past, patients who were identified as stable have become unstable after beginning treatment at STRH. Such changes in patients' health are common among dialysis patients and often not easily predicted. This has resulted in unstable patients being dialyzed at STRH because the feeble state of the patient has meant that transport to the WMRH unit would be too risky. Though such situations are unfortunate and can be quite stressful for staff, it was realized by respondents that because dialysis patients can become unstable very quickly such situations are likely unavoidable.

Although it was recommended by the evaluators that patients continue to be selected for admittance to the satellite unit by the nephrologists at WMRH, it was also suggested that there be an increased effort by nephrologists to include staff of the satellite unit as much as possible so that they may be better able to anticipate the arrival of new patients and understand how patients are selected for the unit.

Provincial Coordination

Coordinating the efforts of the involved boards of the community-based unit and the two facilities of the institution-based unit was challenging to say the least. For both sites several informants noted difficulties in communication and decision-making.

It is suggested that such problems could be ameliorated with the institution of a provincial renal coordinator. This solution was suggested during initial meetings regarding the establishment of dialysis units in the province and has been reiterated the evaluations, particularly by key informants of the community-based unit. This individual would be responsible for collecting, evaluating, and disseminating renal failure data. This information could be used to inform decision making on issues related to all aspects of kidney failure and dialysis in the Province. Such an option would remove many of the challenges that have been revealed by the present report, particularly difficulties associated with miscommunication and misinformation between boards and facilities. This individual could also act as a purchasing agent for dialysis supplies and equipment provincially – translating into sizable cost savings to the province. It is suspected that the magnitude of such savings would certainly be more than sufficient to fund the position.

The Future

It is suggested that additional satellite units *not* be developed until such time that an effective service model has been established. As indicated in the present report there are currently two distinct service models for satellite dialysis delivery (i.e., institution-based and community-based) operating in Newfoundland and Labrador. The present report aims to provide insight into the advantages and challenges of each service model. It is suggested that lessons learned from the development and implementation of both models be incorporated into an effective service model for the Province. If it is not feasible that the same model be implemented at all present and future satellite dialysis sites, it is suggested that based on the findings of the evaluations reviewed here, policies and guidelines for both community-based and institution-based models be reviewed and amendments made where necessary. Following the implementation of such amendments and/or the operationalization of a model based on lessons learned from the evaluation of the two units currently in place, it is suggested that an evaluation again be conducted on satellite dialysis services in the Province. Only then might it be feasible to proceed with further development of satellite dialysis services in this province.

Conclusions

A number of positive and negative aspects regarding both institutional-based and community-based satellite models are revealed by the findings of the respective evaluation reports. Backup staffing was noted to be a concern for both models and at this time there is no clear solution to such challenges for either model of service delivery. It is suggested in the present report that guidelines be developed with regard to backup staffing for satellite units. As is evidenced in the evaluation of the Clarenville unit, such guidelines are effective for providing guidance on the appropriate course of action to take in the event that circumstances result in the unit being inadequately staffed. Stakeholders report that the MOU established between EHCSB and HCCSJ has been extremely worthwhile for providing staff with guidance on a number of occasions. A similar agreement between the parent and satellite facilities of the STRH unit would likely have been beneficial. Such an agreement would clearly outline the roles and responsibilities of the respective facilities and thereby eliminate much of the miscommunication between STRH and WMRH.

Management of both service models was an issue, especially for the community-based model. Managers hired for the community based satellite unit had little or no prior experience in the field of dialysis, thus resulting in difficulties regarding direction available for staff who were also new to dialysis nursing. Management issues were also apparent for the STRH unit. Specifically, it was felt that a permanent team leader should be in place at the satellite unit to serve as a contact person for patients, staff of STRH, and staff of WMRH. While the need for a knowledgeable manager is important for any dialysis unit, this need is intensified for units that are staffed entirely by newly trained dialysis nurses. It was noted by staff of both units that the addition of a team leader with considerable experience in dialysis nursing would be tremendously beneficial for the unit and its patients. Additionally, the increase in workload for staff of the parent unit would be less if there were an individual on site who could draw on their experience to resolve problems that are currently addressed to managers and staff of the parent sites.

Open and clear lines of communication between the parent site and the satellite unit are imperative for successful operation of both community and institution based satellites. For the community based unit communication has been facilitated by the Nephrocare computer system. The value of this system is unprecedented as it allows nephrologists to quickly and efficiently provide their patients with care without actually meeting with the individual. This is deemed to be beneficial for satellite units as missed nephrology visits were indicated to be an issue for both models evaluated. This sort of online communication ensures that even when unforeseen circumstances dictate that a scheduled visit be postponed, patients continue to receive a high quality of care as physicians are still able to review patients' health status and make any necessary changes to their care plan.

An established relationship with other service providers, such as clinical nutritionists and social workers, was also found to be essential for the provision of quality care to dialysis patients. A comparison of the evaluations indicate that having the unit housed in a institutional setting has facilitated such relationships as such services are located on site.

In terms of location of the unit, both communities were generally perceived as appropriate for the provision of satellite dialysis care and positive aspects of both institution-based and community-based units were identified. There is no clear answer as to which model provides a higher level of care to patients, and it is likely that the appropriate service model for delivery will vary as a result of geographical location of the unit, availability of space and proximity to the parent site. When financial analysis becomes available for the institution-based unit, cost-efficiency may help more clearly identify the most effective unit for all parties involved. Patient satisfaction is high for both units and it seems that dialysis patients are most grateful to receive services closer to home; both the community-based and institution-based units have most definitely improved the quality of life for their patients, which was identified as one of the main objectives for both sites.

Finally, findings indicate that the provincial coordination of dialysis services would be an asset to the provision of cost-efficient, high quality, regulated care for dialysis patients in Newfoundland and Labrador. It is hoped that the findings of the evaluations of the two models of service currently established in the Province, as summarized in the present report, will provide sufficient insight for the development of a plan of action for satellite units. It is essential that the impact and effectiveness of the satellite units in Clarenville and Stephenville continue to be evaluated such that an effective service model may be developed that is both cost-efficient and capable of providing high quality care to patients. Until such a model has been developed it would be ineffective to implement satellite services in other areas of the province.

[1] Statistics for this section were obtained from the Canadian Institute for Health Information